

HOPE IN PRIMARY CAREGIVERS' EXPERIENCE OF FIRST EPISODE PSYCHOSIS

Jason Miller

Submitted in accordance with the requirements for the degree of
Doctor of Clinical Psychology (D. Clin. Psychol.)
The University of Leeds
Academic Unit of Psychiatry and Behavioural Sciences
School of Medicine

July 2010

The candidate confirms that the work submitted is his own and that appropriate credit has been given where reference has been made to the work of others

This copy has been supplied on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

ACKNOWLEDGEMENTS

Firstly, I would like to thank the young people and their caregivers who took part in this research. I would also like to thank staff from both aspire and PSYPHER who supported me. I would like to thank my parents for their unending support, inspiration and hope throughout. I would also like to thank my supervisors Sylvie and Anjula for their highly valued wisdom, support and advice. Lastly, I would like to thank all my friends and my housemate Lee for their support and encouragement.

ABSTRACT

Introduction: Primary caregivers provide essential care and support to people with psychosis and are often key players within recovery. The recovery model and an expanding research literature suggest that the concept of hope is an important factor in adaptively coping with psychosis and also serves a critical role within recovery. The present study sought to explore how hope featured within the experiences of six primary caregivers of young people with first episode psychosis within the context of two UK early intervention services. Method: Interpretive Phenomenological Analysis was adopted as the methodological framework with which to approach the research and analyse the data. Primary caregivers were interviewed about their experiences of supporting and caring for a young person with first episode psychosis. Results: Five major themes were identified as characterising the experiences of participants. Caregivers experienced a maelstrom of distressing change and loss following the young person's psychosis and struggled to make sense of what was happening. A range of experiences were also described during the young person's recovery and receiving help from services. Hope was described as an important factor in sustaining and motivating caregivers through the demands of care giving and in their efforts to support the young person towards recovery. Discussion: Having experienced a range of distressing and often traumatising experiences, the findings of the present study suggest that caregivers have a range of parallel support and recovery needs. In particular, the findings highlight the need for caregivers and their families to jointly making sense of the young person's psychosis from a very early stage. The findings also indicate that service providers should seek to nurture the hopes of carers and a range of possible interventions are suggested. The experiences described by caregivers within the present study may also have implications for understanding the development of expressed emotion within the context of first episode psychosis.

CONTENTS

ACKNOWLEDGEMENTS	3
ABSTRACT	4
CONTENTS	5
LIST OF TABLES.....	7
LIST OF FIGURES	8
ABBREVIATIONS	9
1.0 REFLECTIVE PREFACE	10
2.0 INTRODUCTION	12
2.1 Psychosis	12
2.1.1 Definitions and Background	12
2.1.2 Psychosis and Recovery	14
2.2 Psychosis and the Family	17
2.3 Early Intervention Services	23
2.4 Hope and Recovery	24
2.4.1 Models and Theoretical Frameworks for Hope	25
2.4.2 Hope and Caregivers	28
2.4.3 Hope and Psychosis	30
2.5 Summary and Aims	34
2.6 Research Questions	35
3.0 METHODOLOGICAL APPROACH	36
3.1 Outline of Methodology	36
3.2 Theoretical Roots	37
3.3 Alternative Methodological Approaches	38
3.4 Sampling	38
3.5 Data Collection	39
4.0 METHOD	41
3.1 Design	41
3.2 Participants.....	41
3.2.1 Recruitment	42
3.2.2 Ethical concerns	44
3.3 Procedure.....	45
3.3.1 Interviews.....	45
3.3.2 Interview schedule	46
3.3.3 Pilot interviews	47
3.3.4 Data analysis	47
3.4 The Reflexive Researcher	48
5.0 RESULTS	50
5.1 Participants.....	50
5.1.1 Margaret	50
5.1.2 Carol	51
5.1.3 Susan.....	52
5.1.4 Denise.....	52
5.1.5 Anne	53
5.1.6 Steve.....	54

5.2 Summary of Super-ordinate Themes	55
5.3 <i>An Episode of Change and Loss</i>	56
5.3.1 The emergence of change	56
5.3.2 Such a different person	57
5.3.3 It affected just about everything in the house.....	59
5.3.4 We were like a prisoner	59
5.4.0 <i>A Struggle to Understand</i>	60
5.4.1 I wish I could understand	61
5.4.2 It's just so frightening at the time not understanding it	62
5.4.3 Not knowing what's going to happen	63
5.4.4 Everybody has a different opinion.....	64
5.4.5 Nobody would listen to me	65
5.5 <i>Getting Help</i>	66
5.5.1. The hardest thing we've ever had to do	66
5.5.2. That's what I call being well looked after.....	67
5.5.3. The services let you down	68
5.5.4. We could of done with.....	70
5.6. <i>Getting back to normal</i>	72
5.6.1 Slowly coming back	72
5.6.2 The ingredients of recovery	73
5.8. <i>Hope Kept us Going</i>	75
5.8.1 Without hope you might as well give up.....	75
5.8.2 That's where my hope comes from	76
5.8.3 That's why I lost it	79
5.8.4 Not hoping for anything extra special.....	80
6.0 DISCUSSION.....	82
6.1 Change and Loss	82
6.2 The Need to Understand	85
6.3 Accessing Help.....	89
6.4 Recovery	91
6.5 Hope.....	93
6.6 Evaluation of Methodology	95
6.8 Clinical Implications	98
6.9 Conclusion.....	101
REFERENCES	103
APPENDIX.....	111
Appendix 1: Service user approach letter.....	111
Appendix 2: Service user information sheet	112
Appendix 3: Caregiver approach letter	115
Appendix 4: Caregivers information sheet.....	116
Appendix 5: Interview schedule.....	119
Appendix 6: Super-ordinate themes	121
Appendix 7: Master themes.....	134
Appendix 8: Reflections.....	136
Appendix 9: Interview reflections.....	144

LIST OF TABLES

Table 1.....	<i>Description of Participants</i>
Table 2.....	<i>Summary of themes</i>
Table 3.....	<i>Themes for Interview 1</i>
Table 4.....	<i>Master Themes</i>

LIST OF FIGURES

Figure 1.....*Model of hope and recovery (Ruscinova, 1999)*

ABBREVIATIONS

FEP: First Episode Psychosis

EI: Early Intervention

EE: Expressed Emotion

CC: Critical Comments

EOI: Emotional Over-Involvement

IPA: Interpretive Phenomenological Analysis

1.0 REFLECTIVE PREFACE

One major source of my interest in the experiences of caregivers and the role of hope within the context of psychological distress are my own personal experiences of recovering from depression during my mid-twenties. I have frequently reflected on and sought to make sense of what was important during my own recovery. During these reflections, the importance of caregivers and the concept of hope have emerged as critical within my thinking.

My parent's experience of supporting and caring for myself began when I telephoned them one evening in a distressed state. I had recently changed jobs and had been working very long hours for quite a while. Concerned that I did not seem my usual self, they collected me from where I was living at the time and brought me back home. I was diagnosed with depression and spent a number of months living with my parents. During this time my parents acted as my primary caregivers, providing me with invaluable support and encouragement.

Since this time I have been very curious about how this experience was for my parents and what kept them going through the challenges of care giving. Undoubtedly, from my perspective, without their support and care the outcome for me could have been very different. I believe I was very fortunate that my parents remained hopeful and positive. I was particularly aware of how their positive comments towards me and their general sense of hope that the future would be okay instilled in me a sense that things could get better and that all was not lost. This was the initial step I believe in motivating me towards recovery and my getting back on with life. I have since become curious about the experiences of caregivers during such times, how do they manage the many challenges of care giving whilst remaining hopeful and positive?

My research interests in the experiences of primary caregivers and the role of hope within the context of first episode psychosis emerged through my many encounters with young people who had and were experiencing psychosis whilst working as an assistant psychologist in an early intervention team. Parents and families were observed as providing essential care and acting as key players within the recovery process. This led me to consider the experiences of primary caregivers and what kept them going through the difficult task of looking after and supporting a

young person with psychosis. Was hope important in this process? What might mental health services do to better support and help these key players of the recovery team? How might the hopes held by caregivers, which seems so important to recovery, be supported and nurtured?

2.0 INTRODUCTION

In order to present the background and aims for the present study, the following section will begin with a brief outline of what psychosis is followed by a description of the *chronicity paradigm* which has, until very recently, represented the dominant discourse relating to severe forms of psychological distress. The recovery model as an alternative and increasingly influential approach to psychosis is then outlined. Literature looking at the impact of psychosis on the family and systemic approaches to understanding and intervention are then described. The concept of hope and its role in adaptively coping with a range of adverse life events and recovery is then introduced together with a number of theoretical models. The importance of hope for primary caregivers is then discussed, followed by a review of studies exploring the role of hope for caregivers within the context of psychosis.

2.1 Psychosis

2.1.1 Definitions and Background

People experiencing psychosis often endure significant distress which can have far reaching consequences both for the individual and those close to them. Thornhill, Clare and May (2007; p.181) describe psychosis as “experiences such as hearing voices other people do not hear, seeing or sensing things other people do not see or sense, holding unusual beliefs (delusions) or beliefs about the malevolent intention of others which seem unwarranted (paranoia).” In terms of prevalence, psychosis is ranked fourth to sixth amongst the causes of disability worldwide; it causes extensive co-morbidity and mortality as well as extensive personal, familial, social, occupational and educational consequences (Kylma et al, 2006). World-wide prevalence estimates for psychosis range between 0.5-1.5%, with an elevated risk for urban born individuals; 10% of sufferers commit suicide, with onset typically between late teens and mid-30s; there is a slightly higher prevalence amongst men, with women often having a better prognosis (APA, 2000).

Since the early work of the German psychiatrist Emil Kraepelin in the late 19th century, and until very recently, mainstream conceptualisations and treatment approaches have largely adopted the view that people with psychosis face lifelong disability and deterioration. This is often referred to as the *chronicity paradigm*

(Ramon, Healy & Renouf, 2007). Kraepelin's work established psychosis as a distinct form of mental illness, and modern psychiatry has a number of roots in his work, such as the development of diagnostic classifications and a medical approach to treatment. Kraepelin outlined psychosis as a distinct form of pathology characterized by a certain pattern of symptoms and disability. Kraepelin used the term *dementia praecox* to describe what he saw as the two distinguishing features of psychosis: being out of one's mind (demented) and having an early or precocious (praecox) onset (Kruger, 2000). On the basis of his early case studies, Kraepelin observed *dementia praecox* as having an irreversible deteriorating course involving life-long disability. He also proposed that the symptoms of psychosis first appeared in adolescence or early childhood and that people experiencing psychosis often displayed an absence of emotion, inappropriate emotional responses, stereotyped behaviour or catatonic postures, inattention, strange perceptions, hallucinations, irrational beliefs (persecution or grandiosity) (Bentall, 2003).

The term *schizophrenia* was first coined by the Swiss psychiatrist Eugene Bleuler, who used the label to describe a separation of affect, cognition and behavior. Unlike Kraepelin, Bleuler did not see schizophrenia as always resulting in extreme deterioration (dementia), nor did he believe schizophrenia always began in adolescence (praecox) (Bentall, 2003). Bleuler did, however, continue to view the long-term outcomes for most people with schizophrenia as extremely bleak (Kruger, 2000).

For most of the twentieth century, the *chronicity paradigm* formed the dominant discourse towards psychosis. This discourse has meant that service users and wider society have seen schizophrenia as a chronic condition involving life-long disability. Implications of this view have been that service users and family members, rather than being hopeful and optimistic, should be guarded in their expectations for the future (Bellack, 2006). That the 'chronicity paradigm' has been the dominant view seems puzzling given that positive stories of people recovering from psychosis have been present throughout the history of the mental health system (Ramon, Healy & Renouf, 2007). Anthony (1993) suggests that the chronicity typically associated with schizophrenia should instead be seen as a product of ineffective health services and community stigma rather than the condition itself. Allot, Loganathan and Fulford (2004) suggest that mental health professionals holding views that schizophrenia is associated with poor long-term

outcomes operates as a self-fulfilling prophecy.

The dominant view that people with psychosis, particularly those labelled with schizophrenia, face life-long deterioration and poor prognosis has continued through mainstream diagnostic systems such as DSM (Diagnostic and Statistical Manual) (Deegan, 1996). Even more recent versions (e.g. DSM-IVTR; APA, 2000) continue to suggest that recovery rates are low and long-term disability is common (Deegan, 1996). Deegan (1996) argues that the mainstream view that people with schizophrenia face poor long-term outcomes is maintained by the arbitrary application of this label to people who experience psychosis for six months or more i.e. those who are likely to be more disturbed with a poorer long-term prognosis. Despite experiencing the same difficulties and psychological disturbance, people who experience psychosis for less than six months are not seen as having schizophrenia. This circular reasoning perpetuates the view that schizophrenia is associated with poor outcomes and a bleak long-term prognosis (Moller & Von Zerssen, 1995).

2.1.2 Psychosis and Recovery

Beginning in the 1980s and 90s, the pessimistic view that people with psychosis experience a deteriorating course of life-long disability has slowly begun to be replaced with a more optimistic and hopeful notion that people who experience severe psychological distress can and do recover. Whilst referred to in a number of different ways (Roberts & Wolfson, 2004), this is commonly referred to as the *recovery model* or *paradigm*. Two major forces in the ascendancy of the recovery model have been the consumer self-help movement and a growing body of longitudinal outcome studies. The consumer self-help movement has consisted of anecdotal stories of recovery by mental health sufferers (e.g. Deegan, 1988; Houghton, 1982; Leete, 1988; Unzicker, 1989) and consumer developed self-help programs, such as the Wellness Recovery Action Plan (WRAP; Copeland, 1997) and Hearing Voices Network (Downes, 2001). In addition, increasingly a growing number of individuals, including mental health professionals, have identified themselves as mental health consumers and have become very influential spokespersons for the consumer community (Bellack, 2006).

Longitudinal studies following a cohort of people with psychosis over time (e.g. Harding, Brooks, Ashikaga, Strauss & Breier, 1987; Huber, Gross, Schuttle &

Linz, 1980) have been instrumental (Kruger, 2000). Perhaps the most widely cited long-term study is that by Harding et al (1987), often referred to in the literature as the *The Vermont Story* cohort, which prospectively followed the course of 269 patients. This cohort all met the DSM-I criteria for the diagnosis of schizophrenia. They were all long stay patients, amongst the most disabled and profoundly unwell in the hospital. They were discharged from hospital to a community hospital-run rehabilitation programme that operated between 1955 and 1965. At a 10-year follow-up, two thirds remained out of hospital but continued to require intensive support and were socially isolated. At a later 25-year follow-up, one half to two-thirds had achieved considerable improvement or recovery. Whilst such research is not without shortcomings (Harding et al, 1987), the replication of such findings in other similar studies (e.g. Huber et al, 1980) suggests that the impact of psychosis can lessen over time and many domains of functioning can be restored (Harding et al, 1987).

Warner (2004) conducted a meta-analysis of over 100 such longitudinal outcome studies conducted throughout the 20th century. The results revealed a substantial rate of recovery, consisting of 20% showing complete recovery and 40% showing social recovery. Reviewing the long-term outcome literature, Warner (2004; p.375) concludes that: "...one of the most robust findings about schizophrenia is that a substantial proportion of those who present with the illness will recover completely or with good functional capacity, with or without medical treatment." Interestingly, outcome studies suggest that recovery rates and long term outcomes are more positive in developing countries, and a range of social and cultural factors within the developing world have been identified as perhaps accounting for this. Such factors include higher employment rates for people with schizophrenia, greater family involvement and higher social inclusion (Warner, 2009).

Drawing on the consumer movement and outcome studies such as those outlined above, Anthony's 1993 paper, first published in the US, is widely seen as introducing recovery as the guiding vision for mainstream mental health services. In this paper, Anthony (1993, p. 15) states:

"...a person with mental illness can recover even though the illness is not 'cured'. Recovery is a way of living a satisfying, hopeful and contributing life even with the limitations caused by illness. Recovery involves the

development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.”

Anthony (1993) describes this vision as having developed in the aftermath of deinstitutionalisation, involving long-term psychiatric patients being moved out of institutionalised care into the community. This created the need for a new and more progressive approach for people with long-term mental health difficulties. Alternative conceptualisations of mental health problems emerged and community services began to try and address the wider needs of service users such as housing, vocational engagement, education and social inclusion. This represented a major departure from the traditional psychiatric focus on symptom relief (Anthony, 1993).

Within the scientific literature, recovery has traditionally been conceptualised as the elimination or reduction of symptoms and a return to pre-morbid levels of functioning (Bellack, 2006). This view depicts recovery as a final outcome or state which fails to take into account cases where major recovery has taken place but some mental health difficulties continue to be experienced. It also excludes cases where a full return to previous levels of functioning has not been possible but some aspects of daily functioning have been restored. Rather than seeing recovery as simply involving symptom relief, increasingly there is recognition that recovery itself is a deeply personal and unique process involving the changing of attitudes, values, feelings, goals, roles and skills (Anthony, 1993). This developmental process may involve the acquisition of new life skills along with the repairing of a deeply wounded sense of self through engagement in meaningful activity (Rusinova, 1999).

The adoption of recovery as the guiding focus for mental health services has been at the heart of a number of service-level initiatives. Davidson (2005) describes a number of such service-level initiatives within the UK, including: social inclusion; service redesign; conceptual changes about the nature of mental health problems; and an emphasis on individual rather than collective solutions. Social inclusion has involved efforts to remove the social and financial barriers preventing people with mental health problems accessing mainstream services and activities. Service redesign has consisted of developing more responsive services such as crisis resolution, assertive outreach, early intervention teams and Support Time and Recovery Workers. Conceptual changes have involved a move away from a notion of illness towards alternative views conceptualizing psychological disturbance as a

shared human process. The idea that individuals should be the architects of their own recovery rather than a recipient of pre-determined care has also been increasingly embraced by services.

2.2 Psychosis and the Family

As well as psychosis having a devastating impact on the individual, the impact on family members can also be extremely traumatic and distressing. For a significant time caregivers have been neglected and marginalized within the research literature, and instead research has tended to focus mainly on the individual. This is puzzling given the essential role of family members in all aspects of care and recovery (Szmuckler, 1996). The involvement and role of family members in looking after and caring for people with psychosis has also increased more recently with a change in emphasis and approach towards treating people with psychosis in the community rather than admitting them to institutional care (Reed, 2008).

The impact of psychosis on family members has traditionally been referred to as 'burden', although this has been criticized for being too negative, portraying only the unpleasant aspects of looking after a person with psychosis, and perpetuating negative stereotypes of mental disorder (Szmuckler, 1996). Szmuckler (1996) argues that 'caregiving' is a more appropriate term rather than 'burden', which is less negatively loaded, including the positive aspects of caring. Marsh and Lefley (2003) identify three major categories for the impact of psychosis on the family: iatrogenic, this refers to interactions with mental health services in which information and suitable support may be lacking; societal, this includes the impact of social stigma and poor expectancies for recovery; situational, this includes the experiential aspects of living and caring for a person with psychosis.

Addington, Coldham, Jones and Addington (2003), reviewing the evidence on the impact of psychosis on family members, report that distress, anxiety, depression and economic strain is commonly experienced. The severity of family member distress often meets the criteria for psychiatric diagnosis. Family members of an individual with psychosis have been reported to have three times the clinical rates of anxiety and depression of the normal population (Jackson & Iqbal, 2000). The impact on the health of family members also includes physical illness and complaints (Schene, Wijngaarden & Maarten, 1998).

During the period when psychosis first emerges, family members often feel helpless, angry, desperate and anxious (Schene, Wijngaarden and Maarten, 1998). They often feel helpless and a loss of control (McCann, Lubman & Clark, 2009). Parents also commonly experience guilt and blame themselves for their loved one's psychosis, citing poor parenting or genetic weakness (Nystrom & Svensson, 2004). Family members also experience loss and bereavement, often grieving for having lost the person they loved and for future goals and aspirations which no longer seem obtainable (Nystrom & Svensson, 2004). Whilst experiencing this range of unpleasant emotions, family members are required to provide demanding levels of care and support as well as becoming accustomed to liaising with health service providers and negotiating treatment for their loved one (Sin, Moone & Wellman, 2005).

Studies have indicated a greater impact on family members of an individual experiencing a first episode of psychosis. Addington, Collins, McCleery and Addington (2005) suggest that this greater impact may be explained due to the family having no prior experience of the condition, the acuteness may seem more mystifying and there may be diagnostic ambiguity. Research also suggests that a greater duration and severity of psychosis often results in a greater impact on family members (Addington et al, 2003).

Psychosis in a relative often involves family members experiencing traumatic role changes, forced on them without warning (Schene, Wijngaarden & Koeter, 1998). Such tasks may involve undertaking aspects of care not typically adopted for another adult, such as support with daily living, managing finances as well as support with social and occupational functioning (Tuck et al, 1997). Family members involved in caring for a person with psychosis may also become isolated and stigmatised (Anderson, Hogarty, Bayer & Needleman, 1984), often providing care with few resources, little specialist knowledge or support from services (Jackson & Iqbal, 2000).

Qualitative studies exploring subjective experiences and accounts have provided powerful insights into the lives of caregivers. Such studies have also been very useful in identifying the support needs of caregivers and how services might address these. A qualitative study by McCann, Lubman and Clark (2009) looked at the experiences of 20 Australian caregivers of an adult child with FEP. A range of themes were identified which characterised their experiences. Caregivers

experienced looking after a young adult with psychosis as a significant burden and responsibility. Caregivers described a range of difficult emotional experiences including loss, sadness, worry and fear. They also described difficulty with trying to balance their care role with other commitments, needing to be constantly vigilant, becoming socially isolated and experiencing financial difficulties. Caregivers also experienced their care role as highly unpredictable, and often believed they were personally responsible for what had happened.

In exploring the narratives of relatives who had been involved in caring for a family member with first episode psychosis, a qualitative study by Barker, Lavender and Morant (2001) highlights the many difficulties and challenges faced by 9 UK caregivers and their loved ones. Relatives described the family member's psychosis as seeming to develop following difficult life events, particularly changes within their interpersonal relationships. During the initial onset, relatives often misinterpreted changes in behavior as normal adolescent behavior, sometimes leading to a delay in seeking help. The person's psychosis also brought about significant disruptions to family relationships, often leading to a sense of loss. The family member also lost their social network and friends, resulting in significant isolation. Relatives also described experiencing stigma towards their loved one, resulting in people withdrawing from the family and increased isolation. The emergence of the family member's psychosis was often bewildering for relatives and contact with mental health services, rather than lessening their confusion, often led them to feel even more bewildered by what was happening. Making sense of what was happening and forming their own narrative appeared essential for caregivers. This suggests that service providers should seek to support caregivers in this process through dialogue and the sensitive provision of information which can be incorporated within their existing knowledge and lay understandings.

Whilst the impact of psychosis on family members is well documented, there has been less research on how carers develop the strength and resilience to continue caring (McCann, Lubman & Clark, 2009). Huang, Sun, Yen & Fu (2008) suggest that two cognitive strategies in successfully coping with the impact of having a relative with psychosis are positive thinking and knowledge acquisition. Research by McCann, Lubman and Clark (2009), described above, suggests that coming to terms with and accepting the changes caused by the young person's

psychosis and accepting the changes in their own circumstances, such as their newly acquired care role, were important in order for family members to cope adaptively. Interestingly, for some caregivers, following the onset of FEP, relationships with the young adult became closer characterized by better communication and emotional warmth (McCann, Lubman & Clark, 2009).

Szmuckler et al (1996) developed the Experience of Caregiving Inventory (ECI), which attempts to provide a broader measure of both the positive and negative experiences associated with care giving. This measure adopts a stress-coping model, suggesting that the wellbeing of family members is associated with how they appraise the impact and consequences of the illness or condition, and this has been replicated in a number of studies (Addington et al, 2003). Similarly, researchers have applied Leventhal's illness perception/self-regulation model (Leventhal, Diefenbach & Leventhal, 1992). This model proposes that the view and understanding an individual holds about an illness or condition will influence the coping strategies they employ to deal with it. Fortune, Smith and Garvey (2005) found that how caregivers viewed their relative's psychosis determined the levels of distress they experienced. For example, viewing a relative's psychosis as chronic and having stronger views about the severity of its consequences led to greater levels of distress. They also found that different ways of coping were associated with varying degrees of distress. Coping through seeking emotional support, the use of religion and spirituality, active coping, acceptance and positive reframing were associated with less distress. Coping through self-blame was associated with higher levels of distress.

Research on *expressed emotion* (EE) within families highlights the importance of family member responses and the relational environment of a person with psychosis. Expressed emotion relates to the emotional aspects of the family environment, such as the experience of critical comments, hostility and emotional over-involvement. Expressed emotion within families has been measured using the Camberwell Family Interview (CFI), and high levels of EE have often been found to be associated with greater levels of impact on family members and psychotic relapse (Kuipers, 2006). High levels of either or both criticism and over-involvement can predict poor outcome in the ensuing nine months after an acute psychosis (Jackson & Iqbal, 2000). The EE literature has been criticized, however, for

implicitly suggesting that they are to blame for their relative's psychosis (Szmuckler, 1996).

Some research suggests that levels of EE are affected by how family members appraise and understand their relative's condition. Family members believing that a relative's condition is within their control can often lead to negative affective and behavioural responses (McNab, Haslam & Burnett, 2007). Patterson (2005) suggests that high levels of EE may also be linked to family member's appraisal of loss following a relative's psychosis. Emotional over-involvement may develop as an adaptive way of responding to the crisis of a relative developing psychosis, and possibly as an attempt to restore the family environment back to how it was before their psychosis (Patterson, 2005).

Despite the extensive impact of psychosis on family members and the essential support and treatment role they play, historically family interventions targeting the needs and difficulties of family members have often been neglected (Marsh & Lefley, 2003). Biological and genetic explanations for psychosis have often meant that family and psychosocial interventions have received less recognition (Marsh & Lefley, 2003). More recently, however, a strong evidence base for family interventions and family therapy has been developed, and family interventions have become recognised as an evidence-based treatment (Addington et al, 2005). A review by NICE (2003) of 18 RCTs (Randomized Control Trials) found that family interventions are effective in reducing relapse, both during treatment and at follow-up, and in reducing hospital admissions. As well as helping to reduce relapse and hospitalisation, Addington et al (2001) in a 3 year evaluation of the Calgary Early Psychosis Program (EPP) in Canada, report that family interventions can also be effective in reducing levels of family member distress. This is also reported by Kuipers (2006) who suggests that family interventions are effective in reducing the impact of psychosis on family members.

Throughout the development of family therapy practices, different systemic models for understanding psychosis have emerged. Bertrando (2006) describes four major phases in the development of systemic ideas and psychosis: conjoint family therapy; anti-psychiatry; Milan systemic therapy; psychoeducation. Milan systemic therapy identifies psychosis as developing within the context of family interaction patterns, the role of the therapist being to facilitate the development of alternative and less problematic ways of understanding and interacting with one

another. Family interventions targeted at families with high levels of EE have also been reported as effective in reducing relapse (Kuipers, 2006). In terms of the mechanisms by which such family interventions may operate, Kuipers (2006) proposes that family interventions operate by reducing the emotional climate of the family, high levels of emotional expression and family stress often act as triggers for an individual with a biosocial vulnerability for psychosis. Likewise with the literature on EE, such models of interventions implicitly suggest that family members are causally responsible for their relative's psychosis.

Postmodern systemic approaches to psychosis, such as the Open Dialogue approach, offer a very different approach to traditional models of family therapy. For such approaches, neither the service user or their family are seen as causally responsible or as an object of treatment. Instead, both are seen as valued and active partners in the recovery process. The Open Dialogue approach was pioneered in Finland by Jarkko Seikkula and his colleagues (Seikkula & Olson, 2003) and involves the commencing of treatment meetings immediately following an episode of psychosis and throughout its duration. Where possible, these meetings are conducted in the service user's home and bring together the young person in acute distress, the mental health professionals involved in their care and all other important people such as friends and family. The function of these meetings is to facilitate dialogue between the members of this social network towards making decisions about the person's care and to develop a way of understanding what has happened. The approach is based on three major principles: the tolerance of uncertainty, dialogism and polyphony. Unlike Milan systemic therapy, there is no object or structure to be changed by therapy. The therapeutic aim is the construction of a verbal language which creates meaning for the person's psychotic experiences through open dialogue and discourse.

The Open Dialogue approach is well supported by a range of outcome studies, and services throughout Scandinavia have increasingly established this as their way of working with new cases of psychosis. Research suggests that cases treated using this approach require less frequent and shorter hospital admissions, lower rates of neuroleptic medication, and show better outcomes at follow-up, including better employment rates, reduced relapse and disability benefit claims (Seikkula & Olson, 2003).

2.3 Early Intervention Services

Given the extensive impact of psychosis both for individuals, family members and wider society, early intervention services have been developed as an effort to improve the outcomes for young people with psychosis and to prevent long-term disability. Within the UK, early intervention (EI) services for young people with FEP have been developed over the past decade. Guidelines for treating FEP specify early and urgent referral to secondary mental health services and the prompt initiation of specialist pharmacological, psychological, social, occupational and educational interventions (NICE, 2002). Early intervention services typically work with young people between the ages of 14-35 years experiencing FEP or presenting with early (prodromal) signs of psychosis. Early intervention services apply phase-specific psychosocial and psychotropic interventions to improve long-term functioning and minimize personal, familial and societal cost. They are characterised by three major preventative types of intervention: pre-psychotic (prodromal) intervention; early detection of fully fledged psychosis and intensive treatment; and maintenance of recovery through the *critical period* (McGorry, 2000). Pre-psychotic intervention involves identifying and intervening with cases displaying early or prodromal signs of psychosis. Such people have an *at-risk* mental state which may, if left unattended, develop into full-blown psychosis (McGorry, 2000).

Early detection of FEP involves attempting to reduce treatment delay through intervening at the earliest opportunity in new cases of psychosis, so attempting to optimise recovery and minimise longer term disability. Reducing the duration of untreated psychosis (DUP) has become a key target for early intervention services in the UK (Cratsley, Regan, McCallister, Simic & Aitchison, 2008). Efforts to reduce DUP involve educating community services (e.g. teachers, police, social workers etc.) and other professionals who are likely to have first contact with such new cases about the early signs of psychosis and what action to take etc. Whilst debate continues around the issue of DUP, a number of research studies suggest that the length of DUP is associated with clinical outcome. Clarke et al (2006), in a prospective follow-up study, report that longer DUPs are associated with poorer symptomatic and functional outcomes after four years. Norman, Lewis & Marshall (2005) suggest a correlation between shorter DUPs and positive clinical outcomes for people with FEP, particularly the remission of positive symptoms.

Whilst the debate about DUP and clinical outcomes is likely to continue, when considering the psychological impact of psychosis for both the individual and their family, as discussed above, delays in accessing services can prolong their distress and increase chances of relapse and also suicide (Reed, 2008).

Maintenance of recovery through the *critical period*, widely seen as three years following the episode, involves attempts to address the full-range of needs of service users and their care systems within an optimistic and integrated framework (McGorry, 2000). To ensure recovery, maintaining therapeutic alliances during this period is an important task for EI services. Maintaining this alliance requires EI services to be sensitive to the needs of service users and their families, and being youth-friendly in their approach and ethos. Key elements identified by service users of EI services include the 'human' approach as being key to the recovery process, being involved in treatment decisions, flexibility of appointments, high staff to service user ratio, reduction in psychotic symptoms, increased confidence and independence and the provision of daily structure (O'Toole et al, 2004).

2.4 Hope and Recovery

A developing research literature suggests that *hope* plays an important role in recovery from and successfully coping with a range of adverse life events (Snyder, 2000). Within health settings, the view that hope is an essential ingredient within recovery and adaptive coping is gaining increasing coverage. Dorsett (2010), in a review of research findings across a wide range of areas, suggests that hope has a positive role in facilitating academic performance, athletic performance, interpersonal life satisfaction, physical health, recovery from mental health problems, palliative care, goal achievement, recovery from psychological problems, goal centredness and self-efficacy.

As outlined above, the notion of hope is integral to the recovery model, and service user accounts of their own recovery (e.g. Deegan, 1988; Houghton, 1982; Leete, 1989; McDermott, 1990; Unzicker, 1989) have added increased credibility to the acknowledgement of hope within the recovery process. Lovejoy (1982) argues that recovery cannot occur without hope as hope provides the person with the essential elements of recovery: the courage to change, try and to trust. Encouragingly, hope has been increasingly embraced by international and national

mental health policy (Clarke, 2009). For Herth and Cutcliffe (2002) the task facing researchers is not to explore whether hope makes a difference, but to understand how these differences are made and in what ways hope is engendered and sustained.

2.4.1 Models and Theoretical Frameworks for Hope

There are a range of definitions and models of hope. These can be broadly categorised as either uni-dimensional or multi-dimensional. A uni-dimensional approach is characterized by the definitions applied by Miller (Miller & Powers, 1988) and by Snyder (Snyder, 2000). Uni-dimensional approaches conceptualise hope as existing on a single linear scale between hopelessness and hopefulness. Miller defines hope as a cognitive state of being characterised by an anticipation of continued good state, an improved state or release from entrapment. Snyder conceptualizes hope as involving an interaction between having the motivation (agency) to pursue desired goals via certain routes (pathways). According to Snyder, hope is a cognitive state from which positive emotions flow.

Snyder has written extensively on hope and its application. In his early work, he observed how people were motivated to distance themselves from bad outcomes and reduce the distance between themselves and their positive life goals (Snyder, 2000). Snyder developed the notion that goals were the anchor points of hope (Snyder, 2000). In subsequent work, he proposed that people think about workable routes (pathways) to their goals and also their willingness (motivational agency) to use these in order to obtain their goals. These pathways and agentic thoughts combine to provide continued goal directed thinking: hope. When barriers are encountered in the pursuit of certain goals, people seek alternative routes, and following these alternative routes may require increased motivation. Snyder's (2000) theory also offers an account of the process by which an individual may lose hope. Essentially, a person loses hope when they are blocked from obtaining their goals and hope resources are insufficient to overcome the blockage. When faced with blockages, Snyder theorises that hope is depleted through a series of stages: rage, despair, and apathy. However, the assertion that hope is lost in this way is open to the general criticisms levelled at stage theories; they do not allow for any human complexity or variation. Snyder also fails to offer any evidence supportive of his theory.

Multi-dimensional frameworks suggest that hope is constructed from multiple interconnected entities. Dufault and Martocchio (1985) developed a multi-dimensional model of hope through research with cancer patients. Their model conceptualises hope as a dynamic life force rather than trait-orientated and uni-dimensional. Hope is characterized as having two major spheres, *generalized hope* and *particularized hope*, each having six dimensions: affective, cognitive, behavioural, affiliative, temporal and contextual. *Generalized hope* describes the general sense that the future will bring positive experience (e.g. being happy) and *particularized hope* describes the sense that the future will bring some specific goal-oriented experience (e.g. getting married).

Nekolaichuk, Jevne and McGuire (1999) address some of the shortcomings of Dufault and Martocchio's (1985) research by using a much larger and broader sample than just cancer patients. They employed a technique based on Osgood's semantic differential (Nekolaichuk et al, 1999) for quantifying connotative meaning in order to develop a model which captures the personal and subjective, rather than the denotative, nature of hope. Nekolaichuk et al's (1999) analysis revealed three major dimensions which comprise the experience of hope. These are personal (personal spirit), situational (risk) and interpersonal (authentic caring). The personal dimension relates to the elements which comprise the subjective meaning of hope for an individual (e.g. valuable, desirable). The situational dimension relates to the situational elements within which hope is experienced (e.g. stable, certain). The interpersonal dimension relates to the interpersonal elements of hope (e.g. honest, warm). An individual's experience of hope exists within these three dimensions as opposed to a point on a continuum from hopelessness to hopefulness (Nekolaichuk et al, 1999).

Positive psychology provides a useful theoretical framework for understanding the role of hope in recovery. Hope is seen as generating a sense of well-being about the future, and such emotional states are seen as essential in generating psychological health and well-being (Duckworth, Steen & Seligman, 2005). Positive psychology emphasises the role of positive experiences and emotions in the relief of psychological distress, stressing that well-being does not equate to simply relieving a person from their distress. Therapeutic interventions utilizing elements of positive psychology have a growing evidence base supporting their efficacy (Seligman, Steen, Park & Peterson, 2005). Such interventions focus

on generating positive experiences and emotions through practical exercises and tasks (Seligman, Rashid & Parks, 2006). This approach implies that psychological states such as hope can be nurtured in a practical way and are important for psychological well-being and recovery from distress.

A number of other established psychological theories overlap with some of the elements of hope (Snyder, 2000). For example, Seligman's theory of optimism implies that being optimistic is an adaptive way of coping with adversity. For Seligman, optimism is a style of attribution characterized by the way in which negative events are understood. Optimistic individuals attribute negative events as causally related to factors which are external, variable and specific. A state of helplessness follows attributions for such events which are internal, stable and global. This differs slightly from the notion of hope however, as the motivation for optimism, according to Seligman, is to increase the distance from past negative events, whereas with hope the motivation is to reduce the distance to future positive events or goals.

Bandura's (1997) theory of self-efficacy is an adaptive means to pursue a specific goal, and this also overlaps with hope (Snyder, 2000). Self-efficacy involves a cognitive analysis of the capacity required to obtain a specific goal. A person may choose to pursue a specific goal if their analysis suggests they have the capacity required. This differs from hope however, in that self-efficacy is goal-specific, whereas the notion of hope applies to goals which are more general (cross-situational) and ongoing.

Hope also relates to theories of self-esteem (Snyder, 2000). Self-esteem is a dimensional concept people hold of themselves which generates an attitude of self-approval or self-disapproval. A person's level of self-esteem may be based on how capable they view themselves of achieving certain goals. Increased self-esteem may be generated by hope that such goals are obtainable.

Within the hope literature, the notion of *false hope* is also discussed (Kwon, 2002). *False hope* is seen as maladaptive and occurs where expectations and response strategies are based on illusions rather than reality; when inappropriate goals are pursued; or when poor methods or strategies are used to achieve desired goals. Snyder, Rand, King, Feldman and Woodward (2002) to evaluate the tenets of false hope applied Snyder's theory of hope. They conclude that there is a lack of evidence supporting the notion of *false hope*.

A range of measures have been developed which attempt to quantify hope. Three of these are the Dispositional Children's Hope Scale (Snyder et al, 1997; Snyder et al, 2002), State Hope Scale (Snyder et al, 1996; Snyder et al, 2002) and the Adult Dispositional Hope Scale (Snyder et al, 1991; Snyder, 2002). All of these scales are internally reliable and have received good concurrent and discriminant validity (Snyder et al, 2002). Higher scores on these scales have been shown to be beneficial across a range of psychological, health and outcome domains (Herth & Cutcliffe, 2002).

2.4.2 Hope and Caregivers

Within the context of illness and distress, there is the recognition that hope emerges through a relational process (e.g. Anthony, 1993). When a series of barriers are encountered or the barriers are too great, goal-directed behaviour is likely to cease and a state of apathy may ensue. When hope resources are exhausted, the social and relational environment can be critical. Often the hope of supportive others can be the motivating source for recovery (Ruscinova, 1999). Caregiver's hope that a person can overcome adversity or illness creates a supportive setting for the recovery process. Competences held by caregivers that generate hope include positive beliefs about the person, their own capacity to tolerate uncertainty, their motivation to promote better outcomes and hope inspiring resourcefulness (Ruscinova, 1999).

Ruscinova (1999; see Figure 1) developed a model which outlines the cyclical process of hope generation and recovery through supportive relationships. Within this model, there is a cyclical relationship between supportive relationships, hope and the recovery process. Supportive relationships generate both internal, including hope, and external resource development. This in turn promotes the recovery process, which cyclically generates new supportive relationships, hope and further recovery.

There is a growing literature on the role of hope for parents within the context of physical illness, disability and life-limiting conditions. Kylma and Juvakka (2007) found that hope was central to parents coping with an adolescent child with cancer. Hope was observed to sustain life and helped parents to endure the challenges they faced as a result of the child's cancer and also their death. Parental hope also had an impact on the child's ability to cope and generated hope in the

child themselves. Factors endangering and engendering hope were related to several dimensions of family life. These factors related to the adolescent, the adolescent's cancer and health status, the care received and the care-giving personnel, continuation of life, the parent him- or herself, economics, other people, faith and family pets (Kylma & Juvakka, 2006).

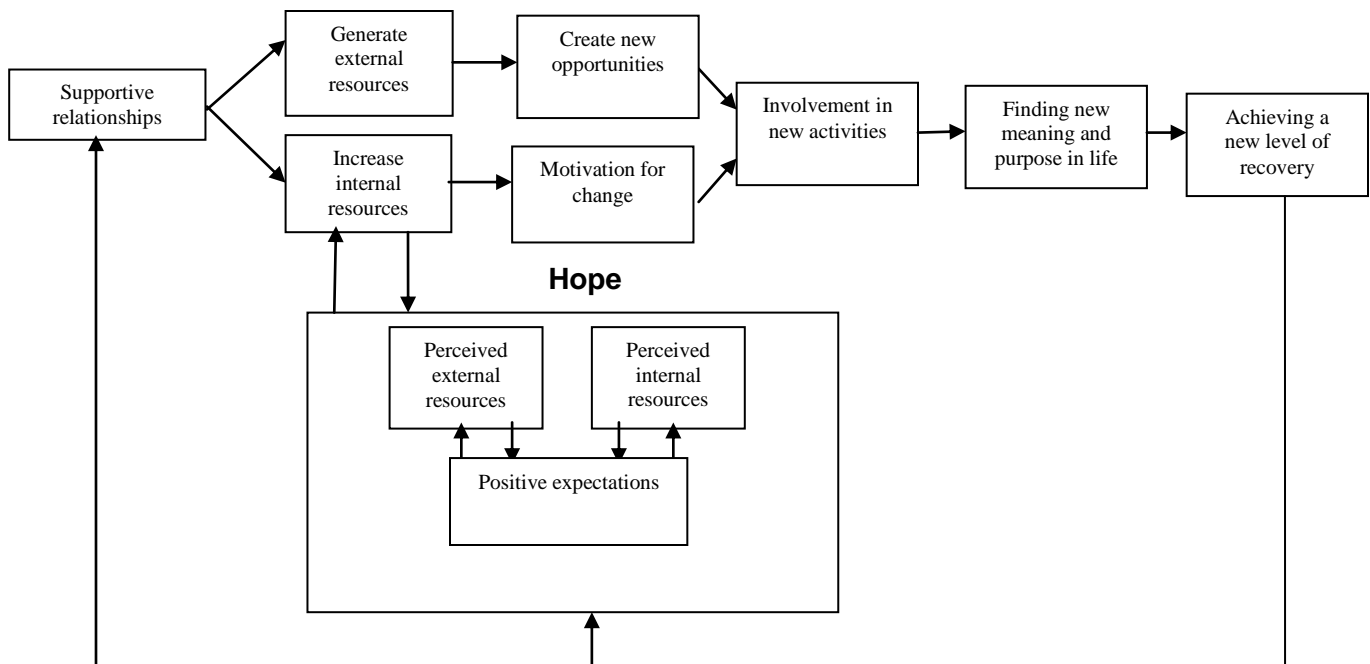


Figure 1
Model of hope and recovery (Ruscinova, 1999)

Wong and Heriot (2008) suggest that a transactional model is useful for explaining why some parents and children cope and adjust well and why others cope and adjust poorly. A transactional model refers to how parental coping interacts with child adjustment, whereby adaptive and helpful ways of coping by parents generate better adjustment and health outcomes for their offspring. Coping refers to the behavioural and cognitive efforts individuals use when managing stressful situations. Looking specifically at a sample of 35 Australian parents of a child with cystic fibrosis (CF) aged between five to twelve years, they applied a range of measures assessing parental coping, health and adjustment. They also applied a measure of vicarious hope and vicarious despair (Vicarious Futurity Scale). Vicarious hope relates to expectations held by caregivers that the future will bring positive events for their loved one, vicarious despair relates to expectations that the future will bring undesirable events for them. Wong and Heriot found that

the coping strategies employed by parents had an impact on both their's and their child's health and adjustment. For example, parental self-blame was most associated with parental and child maladjustment. Levels of vicarious hope and vicarious despair were associated with child mental health, levels of vicarious despair were associated with parent anxiety and levels of vicarious hope were associated with parental emotional impact. Wong and Heriot concluded that hope and despair are distinct from coping, and provide an additional insight into the way children and parents adjust to severe physical illness. They also describe the implications of their research for clinical interventions including targeting support for parents who are coping in ways associated with poor adjustment and have low levels of hope and high despair. However, the small sample size, age range of the children and specific condition (CF) limit the generalisability of these findings to other clinical populations such as psychosis, for example.

2.4.3 Hope and Psychosis

Studies have begun to explore the role of hope in adaptive coping and recovery from psychosis. A review by Kylma, Juvakka, Nikkonen, Korhonen & Isohanni (2006) on the research literature relating to hope and psychosis identified seventeen studies on hope in those experiencing psychosis. Amongst these studies, Landeen, Pawlick and Woodside (2000) emphasize the subjective experience of those experiencing psychosis as most predictive of levels of hope. They found strong relationships between hope, subjective ratings of health and quality of life but not symptom severity. Higher levels of subjective health and higher ratings of quality of life were associated with greater hope. Kirkpatrick, Landeen, Woodside and Byrne (2001) looked at strategies employed by people with psychosis which generate and maintain hope. Amongst those identified were; maintaining relationships, experiencing success, taking control and finding meaning in their experiences. Lysacker, Campbell and Johannesen (2005) found that people with schizophrenia who show high levels of insight and hope adopted the most adaptive coping strategies, while those with high levels of insight but low levels of hope adopted the least adaptive coping strategies.

Perry et al (2007), in their interviews with service users following FEP, identified three major influences on levels of hope. These were making sense of their psychotic experiences, being detained and social integration. Being able to

make sense of their psychotic experiences and being socially integrated were important in increasing levels of hope. Being detained in an inpatient unit was cited as reducing levels of hope.

The review by Kylma et al (2006) found three studies looking at hope for caregivers of a relative with a long-term diagnosis of schizophrenia or other long-term mental health problems. No studies were found looking at caregiver hope within the context of FEP. The small number of studies conducted suggests that caregiver hope as an area of research has received little attention. In addition, none of these studies were conducted in the UK. George & Howell (1996) used a phenomenological approach to examine the experiences of five Australian caregivers and service users with up to a five year history of schizophrenia following re-hospitalisation. Analysis using a comparative method identified five themes within service user and caregiver accounts. Amongst these themes, caregivers reported being hopeful that re-hospitalization would relieve the person of their psychological difficulties and that it would lead to suitable accommodation being found. Service users hoped that that the admission would facilitate new relationships and the gaining of access to accommodation more suited to their needs. Amongst the less positive themes included admissions reinforcing frustrations with the mental healthcare system and lessening perceptions of control, both of these often reduced levels of hope. George and Howell concluded that it is essential for family members and caregivers to be involved in all levels of care and treatment in order to optimize clinical outcomes and reduce readmission rates. They also suggest that practitioners should aim to instill hope through building stronger relationships with both service users and their family and providing connections with strong role models.

Tuck et al (1997) conducted interviews with 9 US primary caregivers of male adult children with a history of psychosis of up to ten years. Phenomenological interviews began with the question “tell me about your experience of caring for your child with schizophrenia?”, this was followed by a series of subsequent prompts such as “what was that like for you?” As part of their analysis they consulted with a research group as a means of quality checking their analyses. The analyses identified a range of themes characteristic of the challenges and difficulties which caregivers faced. Parents struggled to reframe events following the emergence of their adult child’s psychosis as normal, tried to adjust to the experience of seeking

help from various services and professionals, had to deal with a transformation and loss of the adult child they knew, experienced changing levels of hope and endless caring and attempted to find meaning in their experiences whilst trying to preserve their own sense of self. Hope both sustained parents in their struggle to provide care and also exposed them to disappointment and renewed grief. Signs of recovery were found to increase levels of hope, and signs of deterioration and relapse were associated with a lowering in levels of hope. Parental narratives showed a temporal split into accounts before and after the diagnosis. Although narratives had a beginning and middle, they were characterized by the lack of an ending, suggesting that their care role was perceived as relentless and unending. Implications of the findings for practice include the need to listen to the difficulties faced by caregivers and to address their needs through education about the diagnosis and the support available to them, pursuing extra-familial activities and maintaining their own health and well-being (e.g. family support groups), and clear and open communication between mental health professionals and the family. However, the findings of this study have limited generalisability to the UK and the sample recruited does not include the parents of female service users, and so has limited utility in understanding the experiences of caregivers of female service users.

Bland and Darlington (2002) looked at the importance of hope for caregivers of people with enduring schizophrenia in Australia. They conducted semi-structured interviews with 16 family members (8 mothers, 2 daughters and 6 partners) of a person with a diagnosis of schizophrenia (n=9), bi-polar (n=4), drug-induced psychosis (n=1) and an organic syndrome with major depressive symptoms (n=1). In their interviews participants were firstly asked to describe experiences, stories and events when hope was important, in which they either gained or lost hope. Secondly, participants were then asked a series of questions directed at hope within the context of caring for their loved one. An ethnographic method of analysis was employed to examine the interview data. Interestingly, many participants had difficulty defining what hope meant for them, although a close relationship between loss and hope emerged. For family members, loss, as a result of the long-term mental health problems, was seen to reduce levels of hope, whereas signs of recovery increased their sense of hope. Important sources of hope included a diverse range of influences including family and friends, healthcare professionals,

religious beliefs and general positive attitudes and disposition. In terms of the service provided by professionals, aspects which increased levels of hope in family members were: practical support, availability at times of crisis, involving family members in overall care, the human qualities of the worker and their capacity to encourage and support. Families were also found to be most vulnerable to a loss of hope at times of relapse, and family and caregivers remaining hopeful during such times was extremely important for the service user. Bland and Darlington concluded that hope was integral to the complex process of caregivers adjusting to their loved one's condition and served as a protective factor against the negative aspects of their experience resulting from the condition. Implications for practice are that hope is central to recovery and that clinicians should seek to nurture hopefulness in family members by supporting them sensitively through periods when their hope may be challenged, such as during acute crises, for example.

More recent studies have also looked at the role of caregiver hope within the context of looking after a family member with psychosis. A longitudinal study in India by Ganguly, Chadda and Singh (2010) looked at the coping strategies employed by 100 caregivers of a family member with a diagnosis of schizophrenia or bi-polar disorder. A range of coping strategies were described, including: developing compassion in caregiving, hoping for a better future, developing faith in God, participating in religious practices, and helping others with a similar problem. In terms of how hope featured in caregiver's efforts to cope with the challenges they faced, hope appeared to sustain them through their difficult experiences by providing a sense of optimism that their circumstances would improve over time.

McCann, Lubman and Clark (2009) suggest that for Australian caregivers of a young adult with FEP, maintaining hope provided them with the strength to carry on caring. Being hopeful for the future enabled caregivers to endure the difficulties they faced, and the nature of their hopes were found to be both particularized, such as towards specific goals and were also more generalized. Caregiver's sense of hope was experienced as transitional, fluctuating between times of hopefulness or optimism and times of hopelessness or pessimism in response to a range of contextual influences. One major influence on levels of hope was the current well-being of their loved one; levels of hope and optimism increased during times when their loved one was perceived as showing signs of recovery, and levels decreased during times of crisis or deterioration. Caregivers frequently

reminding their loved one that their situation will improve and their future will be much brighter than their current situation suggests, was also described as having an important role in fostering the hopes of their loved one.

2.5 Summary and Aims

The following is a summary of the literature reviewed above. As outlined, psychosis has a devastating impact both for the individual and their family across many domains. Whilst the dominant discourse relating to psychosis for many years has been the chronicity paradigm, in recent times a recovery paradigm has infiltrated clinical practices for people with psychosis. The recovery paradigm is characterized by hope and optimism that people with severe mental health problems can and do recover, and also go on to lead meaningful lives. Whilst a range of frameworks and definitions of hope exist, across many forms of disability, illnesses and traumatic life events, hope has been associated with adaptive coping and adjustment responses and also appears integral to the recovery process. Whilst there are a number of studies examining the importance of hope for the individual, caregivers have received less attention. Studies conducted within the context of physical health conditions suggest that hope amongst primary caregivers has a very important role in terms of their own and their loved ones efforts to cope and adjust successfully to the condition and also functions to promote the recovery process. A small number of studies have looked at the role of hope for caregivers of a relative with long-term psychosis. Such studies suggest that hope enables caregivers to cope adaptively with the many difficulties and challenges they face. However, there is a relative lack of research exploring caregiver hope within the context of FEP in the UK; the present study will attempt to address this gap. Given the objective of EI services in promoting better outcomes for young people with psychosis and the importance of caregivers and hope within the recovery process, such research has a range of clinical implications. Such implications include service providers having a better understanding of caregiver experiences and need, factors which influence their sense of hope and the ways in which their hopes can be nurtured and sustained.

2.6 Research Questions

The research questions for the present study are as follows:

1. What are the experiences of primary caregivers of young people experiencing FEP involved with an EI service?
2. In what ways does hope feature within the experiences of primary caregivers?
 - a. How is hope conceptualized within their experiences?
 - b. What experiences influence caregiver hope?

3.0 METHODOLOGICAL APPROACH

The following section briefly outlines the methodological approach adopted by the present study, the theoretical rationale for this approach and theoretical issues relating to its application.

3.1 Outline of Methodology

In order to explore how hope features within the experiences of primary caregivers for a person with FEP, a qualitative design seems most appropriate. Qualitative designs provide a flexible framework within which to explore how individuals make sense of certain events or phenomena, the meaning these events or phenomena have and how people have lived through or cope with these (Willig, 2009). They are data-driven, whereby findings are developed through a bottom-up process rather than one which is top down, such as in quantitative studies whereby findings are driven by hypotheses or predictions drawn from pre-existing theory. Qualitative designs are applied within naturally occurring settings or contexts and are pertinent in exploring phenomena for which there is little current understanding and to also generate new insights (Robson, 2008).

The present study will employ Interpretative Phenomenological Analysis (IPA). Interpretive Phenomenological Analysis is an approach which takes the epistemological position that psychological inquiry should seek to understand how individuals experience and make sense of significant events within their lives. Proponents of IPA, Reid, Flowers & Larkin (2005; p.20), describe the understanding of experience as "...the very bread and butter of psychology..." The relatively short history of IPA can be traced back to a publication by Smith (1996), within which Jonathan Smith, the main developer of the approach, makes the case for a qualitative methodology tailored to providing insights into how individuals uniquely experience and make sense of events within their lives. He advocates the use of such qualitative methods within health psychology as a way of expanding and greatly enriching the understandings derived from largely quantitative approaches (Smith, 1996). Whilst initially applied within health settings, the use of IPA has since been applied within a quickly expanding range of professional fields such as clinical

and counselling psychology and also within social and educational psychology (Smith, Flowers & Larkin, 2009).

3.2 Theoretical Roots

Interpretive Phenomenological Analysis derives its theoretical roots from three major areas of philosophy: *phenomenology*, *hermeneutics* and *idiography* (Smith, Flowers & Larkin, 2009). *Phenomenology*, developed by philosophers such as Husserl and Heidegger, emphasises an examination of experience, looking at how this occurs and in its own terms (Smith, Flowers & Larkin, 2009), or as Husserl phrased it, 'back to the things themselves'. Through a process of reflection, phenomenology aims to understand how individuals uniquely experience and make sense of their worlds. *Hermeneutics* is a philosophical endeavour concerned with exploring the process of interpretation and how this process is shaped. According to hermeneutics, our understandings of the world are constructed through a process of interpretation, and the interpretations we make are unavoidably shaped by our own positions within the world. Hermeneutics suggests therefore that our interpretations are subjected to a range of influences such as preconceptions and assumptions, and as a consequence our interpretations can never be truly objective. *Idiography* rejects a purely nomothetic approach, and stresses the need for a focus on the particular. That is, rather than aiming to make generalisations across populations, idiography emphasises the need to study in detail and in-depth the experience of an individual.

These philosophical influences are foundational with regard to IPA's epistemological position. IPA emphasises a detailed phenomenological examination of individual experience and sense-making. Drawing on hermeneutics, IPA also emphasises the interpretive nature of this endeavour, often referred to as the *double-hermeneutic*, whereby the researcher is attempting to make sense of a research participant's sense-making. The focus of IPA is idiographic, in that its foremost aim is the detailed and in-depth examination of an individual's experience, situated within their own context. Only following a close examination of each participant's account does IPA subsequently look at divergence and convergence between participants (Smith, Flowers & Larkin, 2009).

3.3 Alternative Methodological Approaches

In terms of the present study, a range of alternative qualitative approaches were considered. One such method was grounded theory. This method, originating within sociological research, assumes the epistemological position that social phenomena have structure and follow certain rules; the end-product of analysis is the development of a theory or framework with which to understand such phenomena (Willig, 2009). Whilst this method may be appropriate for future studies seeking larger samples and theoretical frameworks generalisable to all primary caregivers, the epistemological position and approach of grounded theory were not seen as fitting with the idiographic and exploratory aims of the present inquiry. The aims of the present study are to explore and gain an understanding of the experiences of individual caregivers rather than seeking a theoretical framework across a population of caregivers. Narrative analysis was also considered, although this method focuses on how and in what ways stories of events are constructed by participants (Willig, 2009). Discourse analysis was also considered, although this approach focuses on how language is used to make sense of certain phenomena (Willig, 2009). Again, this approach was not seen as being as useful in exploring how individual caregivers think and feel about caring for a young person with FEP but instead would focus on the language they use.

3.4 Sampling

Purposive sampling tends to be used by IPA studies as a means of selecting participants. Purposive samples are reasonably small and consist of individual participants who share a similar experience or perspective of the phenomenon being investigated (Smith, Flowers & Larkin, 2009). In using purposive sampling, a sample's homogeneity is a key concern. In this sense, homogeneity refers to the degree to which a sample can be seen as consisting of people who share a sufficiently similar perspective. A sample's homogeneity may, for example, be influenced by social demographic factors such as age, socio-economic status or ethnicity.

3.5 Data Collection

The primary aim of data collection for studies using IPA is to provide a 'rich', detailed, first-person account of a participant's experience (Smith, Flowers & Larkin, 2009). The term 'rich' refers to the chosen technique for data collection providing participants with the space and time within which they are able to freely and reflectively give an account of their experiences relating to the phenomenon under study (Smith, Flowers & Larkin, 2009). The chosen data collection technique should also aim to provide a detailed first-person account by inviting participants to describe their experiences in depth and at length through a very personal focus on their individual experience (Smith, Flowers & Larkin, 2009).

For studies adopting IPA, semi-structured interviews are a favoured method with which to collect such data. These interviews are easily managed; allow rapport to be developed; allow participants to think, speak and be heard; and are well suited to in-depth personal discussions (Reid, Flowers & Larkin, 2005). Interviews are seen by IPA researchers as a conversation with a certain purpose or focus and may have a varying degree of structure. Their overall aim is for the interviewer to enter the world of each participant (Smith, 2008). IPA researchers are mindful and reflective, however, on the interactional and collaborative processes within the interviewing context which may influence the interview trajectory, and believe that it is impossible for the interviewer to be truly neutral with regards the process of the interview and the data obtained (Rapley, 2001).

Whilst other data collection techniques such as postal questionnaires, focus groups and e-mailed dialogue have been used by previous IPA researchers (Reid, Flowers & Larkin, 2005), and were considered for the purposes of this study, the analysis of such data is complex. Semi-structured interviews were selected within the present study as this method allows for a flexible and exploratory approach to be taken whereby questions could be tailored to each caregiver's context, and unexpected areas emerging during the course of the interview could be explored in greater detail.

Whilst varying in their degree of structure, semi-structured interviews have a schedule which flexibly guides rather than dictates the interview (Smith, 2008). This schedule comprises predetermined questions and prompts, although the order in which these questions are asked can be varied depending on the researcher's

perceptions of what is said and how this relates to the research questions. Also, certain questions from the schedule may be omitted if they are not perceived to be applicable for certain individuals. The wording of questions can also be adjusted for each person being interviewed. In the light of a response, further questions can be added so that areas not previously considered can be explored in greater detail. Within interviews, non-verbal cues can also be recorded which may provide further understanding.

4.0 METHOD

3.1 Design

As previously outlined, a qualitative design was employed and Interpretive Phenomenological Analysis (Smith, Flowers & Larkin, 2009) was adopted as the methodological framework with which to approach the research and analyse the data. In order to construct a reasonably homogeneous sample of participants, purposive sampling was used; all participants were recruited through an EI service and were the primary caregiver for a young person with a history of FEP. Research data was collected through the audio recording of individual semi-structured face-to-face interviews. Interviews were guided by an interview schedule (see Appendix 5. p. 111) consisting of pre-prepared questions and prompts. The recordings for each interview were transcribed verbatim, and transcriptions were analysed using IPA in order to explore and identify experiential themes, firstly for each individual participant, then, through exploring connections and relationships between the themes for each participant, to identify super-ordinate themes which applied across the sample.

3.2 Participants

Six primary caregivers were interviewed about their experiences looking after a young person with FEP. Three primary caregivers were recruited from the EI service in Hull, East Yorkshire and three from the EI service in Leeds, West Yorkshire. Each participant was given a pseudonym. Table 1 displays basic demographic information for each participant, the nature of their relationship with the young person, the young person's age and the estimated date (month and year, where known) for the emergence of their FEP.

Table 1

Description of Participants

Pseudonym	Gender	Occupation	Ethnicity	Relationship to young person	Age of young person at time of interview (years)	Month and year of FEP
Margaret	F	Housewife	White British	Mother	20	March 2009
Carol	F	Admin	Turkish	Mother	20	Easter 2009
Susan	F	Sales assistant	White British	Mother	24	March 2006
Denise	F	Office work	White British	Mother	20	March 2009
Anne	F	Office work	White British	Mother	19	? 2006
Steve	M	IT Consultant	White British	Father	23	? 2007

Note. F= female; M=male

Where Month and Year of FEP begins with ?, the month was not known

3.2.1 Recruitment

As a means of increasing access to potential participants and to assist recruitment, participants were recruited through two EI services. One EI service was located in Hull, East Yorkshire; Psychosis Service for Young People in Hull and the East Riding (PSYPHER). This service is funded by the Humber Mental Health Teaching NHS Trust and provides a service for young people and their families living within the city of Hull and the East Riding of Yorkshire. The other EI service, *aspire*, was located in Leeds, West Yorkshire which provides a service to young people and their families within Leeds. Whilst commissioned and funded by the PCT, *aspire* is

part of Community Links, a mental health voluntary organisation. Both PSYPHER and *aspire* provide a service to young people aged between 14-35 years of age with FEP.

The following recruitment criteria for potential participants were used: in order to ensure some form of recovery process was underway and to exclude cases currently in crisis following a recent incidence of psychosis, only service users who had experienced psychosis at least six months prior were invited to participate; both the young person and their primary caregivers were fluent in written and spoken English; the service user was assessed to have the mental capacity to understand the aims and scope of the research and were able to give their consent; they were known to have someone who had acted as their primary caregiver; and their participation in the research was not felt to present any risk to their engagement and relationship with the EI service.

The recruitment process involved a care coordinator within the EI service approaching young people involved with the service, for whom the above criteria were satisfied, to enquire whether they would be willing to consent for their primary caregiver to be interviewed about their experiences caring for them. Young people were provided with a standardised approach letter (see Appendix 1) together with an information sheet (see Appendix 2) outlining the aims and scope of the research. They were encouraged to take time to think about their decision and to take as long as they required. If willing to consent, service users were then asked to sign a consent form and provide the contact details for the person they identified as their primary caregiver. It was important that the service user themselves identified their primary caregiver, rather than this being assumed, either by the researcher or their care coordinator.

Where consent was given, the care co-ordinator involved then passed on caregiver's contact details to the researcher. The researcher then sent a standardised approach letter to the primary caregivers (see Appendix 3) informing them that consent had been given for them to be approached. This letter was sent with an information sheet (Appendix 4) describing the research and its purpose. If the caregiver decided to participate, they were asked to telephone the researcher in order to organise an interview at a date, time and venue convenient for them. Caregivers and service users were invited to also contact the researcher if they required any further information about the research.

3.2.2 Ethical concerns

Ethical clearance for the study was obtained from the Leeds Central NHS Research Ethics Committee. Ethical issues pertinent within the present study included consent and mental capacity. Service users, from whom consent was requested for an approach to their primary caregiver to be made, were assessed by the EI clinical team member making the participant referral to have the mental capacity to do so. All clinical team members were appropriately trained to do this. Service users and their primary caregivers were also provided with easily accessible information about what the research would involve for them, and it was emphasised throughout that participation was not mandatory, nor would it affect the care they were receiving. Service users and their caregivers were invited to take as much time as they required in order for them to decide whether or not to participate. Throughout this process it was emphasised that their decision could be changed at any time and they were able to withdraw without any consequence for all involved. Formal consent was obtained using a consent form for both service users and their primary caregivers, and a copy of this was kept in the EI service clinical case notes.

As caregivers were likely to have experienced a number of upsetting and difficult events during the time they had been supporting a young person, discussing these within the interview often brought up a range of difficult feelings and emotions. A debrief session followed each interview in which caregivers were invited to talk about how the interview had been for them and to discuss any residual feelings that the interview had evoked. If necessary and consented to by the caregiver, any ongoing concerns with regard to a caregiver were notified to the clinical lead for the EI service so that further support and intervention could be offered.

In terms of maintaining confidentiality, personally identifying data provided on participant referral forms including names, addresses and telephone numbers were kept secure at all times and were securely destroyed following completion of the study. Participants were informed, however, that where serious concerns about the safety and wellbeing of any adults or children occurred during the conducting of the research, these would be notified to the clinical lead for the EI service or emergency services were appropriate. To protect anonymity, interview

data and transcripts were identified by number only. Following completion of the research, participants were offered the opportunity to discuss the research findings. A summary sheet of the findings was also produced and this was sent to all participants who requested this.

Safeguards were also employed to manage potential risk and harm to the researcher. Any emotional and personal difficulties evoked by the content of an interview were managed through supervision with either the field or academic supervisor. Where interviews were conducted at a participant's home, a buddy system was employed, whereby a third party was notified about the location of the interview and instructed to contact them if no contact was received following the expected duration of the interview.

3.3 Procedure

3.3.1 Interviews

Interviews were conducted either at a participant's home or at the clinical base for the EI service. Efforts were taken to ensure the setting for the interview was quiet and comfortable. In order to situate participants, each interview began with the construction of a genogram, through which familial relationships were mapped out and current living arrangements were established. Interviews followed a non-directive schedule, and lasted between 45-90 minutes. The interview schedule was used flexibly, so that the trajectory of each interview could be tailored to each participant's experience. The order of questions was also varied which allowed the interview to flow and rapport to be built. An effort was also made to phrase questions mirroring the terms and language used by each participant. Prompts were also used to explore areas which were not previously anticipated.

Interviews were recorded using a digital recording device. Recordings of each interview were transcribed verbatim and non-verbal communications such as laughter, pauses, sighs, and crying were also noted. So as not to disturb the flow of the interview, specific demographic questions were asked at the end of the interview. Demographic questions related to the participant's gender, age, employment, ethnicity, the nature of their relationship with the service user and time since FEP.

3.3.2 Interview schedule

The non-directive interview schedule consisted of a list of pre-prepared questions and prompts (see Appendix 5). The questions and prompts used were aimed at facilitating participants to talk as openly as possible about their experiences without influencing their responses. All questions were open-ended, neutral and singular (Hunt & Smith, 2004) and gradually explored the experiences of participants in more and more detail. During each interview, an effort was made to phrase questions using the terms and concepts already used by each participant. Also, in interviews where a participant began to talk about experiences relating to an area not covered by the interview schedule, open-ended and neutral prompts were used to explore these in more detail.

The interview schedule focused on participant experiences along a sequence of four major time periods: leading up to the FEP; during the FEP; during the recovery phase; and perceptions for the future. The interview schedule used broad opening questions aimed at inviting participants to freely describe their experiences within each chronological time period followed by questions aimed at providing more analytical and evaluative insights. Following a graduated exploration of experiences within a specific time period, moving from descriptive accounts towards analysis and evaluation, if not already described or referred to by the participant, participants were then asked to reflect on whether hope may have been important to them during a time period. Specific prompts and questions followed participant responses aimed at obtaining more and more detail about how hope may have featured during their experiences.

The construction of the interview schedule followed the five developmental stages outlined by Smith, Larkin and Flowers (2009). Initially the broad areas to be covered during the interview were identified. In the present study, this was how primary caregivers had experienced looking after a young person with FEP and whether and how hope may have been important. A range of topic areas were then developed. It was felt that proceeding along a chronological time sequence (beginning to notice changes in the young person, during their FEP, during their recovery and perceptions of the future) was likely to cover the major areas of primary caregiver experience and that this would be a logical and appropriate

sequence. Appropriately phrased questions and prompts focusing on these areas were then developed. As a means of checking that questions made sense, were appropriate and suitably phrased, drafts of the questions were discussed and piloted with the supervisors for the study. Where issues or difficulties with the questions were identified, questions were subsequently redrafted and brought back for further piloting and discussion.

3.3.3 Pilot interviews

As a means of piloting the interview schedule and gaining familiarity with the interview process, two pilot interviews were conducted. The interview schedule was firstly piloted with my own parents. As well as representing a reflexive effort to help explore and identify some of my own pre-conceptions and assumptions with regards the focus of the study, this was also very useful in ascertaining that the questions made sense and fitted with the experiences of primary caregivers within the broad context of looking after a young person experiencing psychological distress. Secondly, the interview schedule was used with a primary caregiver for a young person with FEP. Whilst the data from this interview was also used within the analysis, this interview was used as a further opportunity to check out the appropriateness, flow and wording of questions. Following both pilots, no revisions were made to the interview schedule, although the process was found to be very useful in terms of becoming familiar with conducting interviews of this kind; particularly the need for the interviewer to actively listen to participants, avoid any interpretive comments and to be continually curious although neutral with regards the accounts given by participants.

3.3.4 Data analysis

The process of data analysis followed was that outlined by Smith, Flowers and Larkin (2009). So as to initiate a close relationship with the data, the first phase of the analysis began with the reading and re-reading of an individual transcript a number of times. This was also done whilst listening to the original recording. Initial thoughts and comments relating to aspects of a transcript were noted in the left-hand margin. The second phase of the analysis involved noting emerging themes in the right-hand margin, and key words from the transcript were used to illustrate these. The third phase involved producing a chronological list of all the emerging

themes. Each individual theme was then laid out on a large surface and those which appeared connected or related to one another in some way were clustered together. An initial attempt was made to label these clusters in some way, and many of these clusters began to form super-ordinate themes. These clusters were then entered into a table with illustrative extracts from the interview (see Appendix 6 for example), and through this process theme names were developed which more closely reflected the terms and language used by participants.

These phases of analysis were then repeated for each subsequent transcript, although this followed a cyclical process, whereby any new theme emerging from a subsequent transcript was looked for in a previous transcript. Once all individual transcripts were analysed, the tables for each transcript were then compared collectively with one another in order to explore relationships and connections across the themes for each. This process led to the development of a master table of themes (see Appendix 7) which characterised the key themes across all transcripts. In order to become established as a super-ordinate theme, the theme was needed to be recurrent in at least a third (or two of the transcripts). Through creating this master table, themes then began to merge with one another to form higher order themes. Theme names were developed through using interview extracts which appeared to most closely capture the essence of the theme.

As a means of quality and credibility checking, samples of the data analysis were checked and discussed with both the academic and field supervisor throughout the analysis phase of the research. Samples checked included the analysis table for individual transcripts and the master table of super-ordinate themes across all transcripts. In the instance of any disparity these were fully discussed and revisions were made. In addition, throughout the data collection and analysis, interpretations and reflections were also discussed within a qualitative research peer supervision group.

3.4 The Reflexive Researcher

As outlined in the Methodology, the use of IPA emphasizes how the researcher's own experiences and sense-making impacts on the interpretive research process (Smith & Osborn, 2008). This is often referred to as the *double hermeneutic*. Within

IPA studies a critical process is for the researcher to be openly reflective on how their own experiences and subject position may impact on the research. In order to encourage a reflexive approach, Langdrige (2007) recommends a series of reflexive questions and prompts for qualitative researchers to consider. Personal reflections in relation to these questions and prompts were documented periodically during the research process: prior to beginning the study, prior to beginning the data analysis and following completion of the data analysis. These reflections are documented in Appendix 8. Throughout the data collection and analysis phases of the study, personal reflections were documented shortly following the conducting of an interview and during the analysis. An example of these can be seen in Appendix 9.

5.0 RESULTS

In order to present the findings from the analysis, a brief description of each participant's family context, the history and circumstances of how they came to be the primary caregiver for a young person with FEP and some personal reflections relating to each interview will firstly be given. A table summarising the super-ordinate themes is then presented. This is followed by a detailed description of each super-ordinate theme and their sub-themes. Interview extracts will be used throughout to illustrate these themes and to also highlight how they apply within each participant's experiential account as primary caregivers.

5.1 Participants

5.1.1 Margaret

Margaret and her husband have two adult daughters. Their youngest daughter experienced an episode of psychosis when she was 19 years of age. The episode began in March 2009, and at the time she was living with her parents and was working as a full-time care assistant in a residential care home. She continued to live with them throughout the episode. Her daughter's psychosis appeared to develop very suddenly, and Margaret's concerns were raised when she began to express some disturbed thoughts after returning home from work one evening. Realising there was something wrong, her husband took her daughter to the local Accident and Emergency service, which was shortly followed by a home visit from the crisis resolution service. Her daughter's psychosis appeared to last for up to two months. She was not admitted into a psychiatric inpatient unit at any stage and she received care from the local EI service shortly following involvement from the crisis service. At the time of the interview, her daughter was showing positive signs of recovery. She had begun to go out with her friends again, was doing some part-time voluntary work and was also doing a counselling course.

During the interview Margaret frequently laughed and joked about what had happened, and humour appeared an important way of her coping with what had happened. My initial reflections following this interview had been that whilst the emergence of her daughter's psychosis had been a significant shock, Margaret had experienced a very quick response from mental health services and good quality

support throughout. Margaret's partner and elder daughter had also been very supportive. These two important sources of support appeared to have been instrumental in her daughter having begun to show very positive signs of recovery.

5.1.2 Carol

Carol and her husband are both Turkish. Whilst Carol was born in the UK, her husband was born in Turkey and came to the UK in his thirties. They have one son who developed psychosis in March 2009 when he was 19 years of age. He had moved away to university in September 2007, and had experienced problems settling in and decided to change courses beginning in September 2008. In November 2008, Carol began noticing slight changes in her son, including him having trouble sleeping. He had returned home for Christmas and prior to him returning to university in January 2009 he had had a big argument with his father, in which he had confronted his father about him saying hurtful things to his mother. Carol and her husband had been experiencing marital difficulties for some time. Her son returned home from university in March 2009, and he began behaving and talking very strangely. He disclosed to his parents that he had been using cannabis for some time. Shortly afterwards he began to deteriorate rapidly, he became increasingly aggressive and his parents needed to restrain him on a number of occasions. He was admitted to a psychiatric unit under section with police assistance after a few days of Carol and her husband trying to manage him at home. He was admitted for two weeks before returning back to his parent's home. At this time the local EI service became involved. At the time of the interview, her son was continuing to live with her and her husband, and was beginning to consider future employment plans and the possibility of returning to university.

My reflections during this interview had been that Carol and her husband had found their son's psychosis as extremely traumatic. During the interview Carol became very upset and tearful; she had clearly struggled to cope with what had happened. Her son's psychosis was described as having occurred at difficult time for the family, and as soon as she began talking about what had happened within the family she immediately became tearful. Carol presented as continuing to struggle with what had happened and appeared very depressed.

5.1.3 Susan

Susan is a single parent; she had separated from her husband approximately ten years ago shortly after he had begun an affair with a family friend. She has two daughters. Her eldest daughter, who was 23 years of age at the time, developed psychosis in March 2006 whilst she was still living at home. Susan's involvement as a caregiver began very quickly when she was called to collect her daughter from work. At this time her daughter presented as very distressed and was expressing thoughts that she was responsible for a series of major errors at work and events on the television. The following day Susan sought professional help, and for a number of years her daughter continued to receive treatment from the local adult community mental health team. During this time, Susan was often required to manage and care for her daughter on her own, with additional support from her parents and other daughter. Sadly, Susan's father died of a brain tumour approximately a year following her daughter experiencing psychosis, further increasing the burden on her. Her daughter became involved with the local EI service when she moved out of her mother's house and re-located to another town nearby. At the time of the interview, her daughter had returned to full-time work, had bought her own flat and was living semi-independently but was continuing to require support from her mother in managing her disturbed thoughts which often seemed to occur at times of stressful life events.

My reflections during this interview were that whilst Susan had appeared to cope very well, as a single parent she had found it very difficult. When asked to describe the impact of her daughter's psychosis on her, she became extremely tearful and upset suggesting to me that many of the difficult feelings which she had experienced were still very raw.

5.1.4 Denise

Denise is married and lives with her partner, together with their three adult children. She has two adult sons and one daughter. Her youngest son's mental health appeared to deteriorate over a long period of time. During the end of his time at secondary school he had become increasingly isolative and gradually stopped attending school. Despite his attendance becoming more and more sporadic, he managed to do well in his GCSEs, and enrolled in to the sixth form. Over the next academic year his attendance again worsened, with him spending increasing

amounts of time in his bedroom. At this point his teachers contacted Denise and her husband expressing their concerns and informed them that his attendance had become so poor that he would no longer be able to continue to attend. This led to both Denise and her husband becoming increasingly annoyed and also confused as to why their son was behaving in this way. Shortly afterwards, her son was taken to A&E following an anxiety attack whilst intoxicated with alcohol, at which point concerns were expressed by medical staff and he was referred to the local EI service. The local EI service continued to meet with Denise for the next 18 months. Despite Denise becoming increasingly concerned about the changes in her son's behaviour, because he was unwilling to acknowledge experiencing any mental health difficulties and was presenting with no immediate risk, no professional help could be given. In March 2009 her son was brought home by the police in the early hours of the morning, having been found wandering the streets. He presented as extremely disturbed, and despite his parent's best efforts, he could not be managed at home and so was sectioned under the Mental Health Act. At the time of the interview, Denise's son was continuing to live at home, and whilst showing some interest in finding employment and joining a football team, he was not taking any action in achieving this and continued to be spending large periods alone in his bedroom.

During this interview I reflected on Denise's frustration and helplessness witnessing her son's deteriorating mental health but being unable help him. Denise and her family had clearly struggled over many years, and I developed a sense of their having had a 'ticking bomb' in the house, having to live with a continual fear that something bad was about happen.

5.1.5 Anne

Anne is married and lives with her husband and son of 19 years of age. She has two older adult children, who both live separately. Her son developed psychosis at the age of sixteen years. Prior to this she had been concerned about his problematic behaviour which seemed to follow the development of juvenile arthritis, which meant he was no longer able to take part in any sports or physical activities. At the time he was referred for assessment by the local Child and Adolescent Mental Health Service but no further action was taken. She described her son as having always been slightly different to her other children, having always had an

imaginary friend and at times stating that he could see people in the house. Following the development of his psychosis, Anne and her family had experienced major difficulties in managing his behaviour and the police were frequently called. He began to use a range of substances and was often attacked when outside due to his bizarre and threatening behaviour. Despite a number of admissions to psychiatric inpatient units Anne and her family were continuing to struggle to manage his disturbed behaviour. At the time of the interview, she stated her son had been referred to a supported housing project and they were waiting to hear whether he would be offered a placement.

During the interview with Anne I reflected on how draining and soul destroying her experiences as a caregiver had been. She expressed considerable anger with not being able to access support for her son and him failing to take responsibility for himself. The impact of his psychosis on the family had been extensive, and I developed a sense of both Anne and her family having reached the limits of what they were able to cope with.

5.1.6 Steve

Steve is a single parent who lives together with his eldest son. He has a second son who lives away at university. He separated from his wife shortly after his eldest son developed psychosis at the age of 19 years. At the time his son had been studying at university. Steve's concerns were raised when he discovered that his son had been self-harming for a number of years. Shortly after returning home from university, because he was struggling to cope, he was admitted to a psychiatric unit for a number of months. Since discharge, he has continued to live with his father with very little contact with his mother. At the time of the interview, the local EI service were involved, but Steve's son had not meaningfully engaged with his support worker and he continued to be extremely socially isolated and needing prompting to get out of bed and to eat and drink.

During this interview I reflected on Steve having been the only male parent I had interviewed, and throughout the interview I found myself looking for differences between his experiences and the female caregivers I had interviewed. Whilst Steve seemed less emotive and more factual in describing his experiences, he had struggled with a very similar range of challenges and experiences as the other caregivers. He stated he did not like talking about his experiences and this was the

shortest interview in duration. As a single parent Steve had clearly found his role as a caregiver extremely isolative and restricting.

5.2 Summary of Super-ordinate Themes

Table 2 lists the super-ordinate themes and sub-themes together with illustrative extracts. Appendix 7 shows the themes and sub-themes present within each interview.

Table 2

Summary of themes

Super-ordinate and Sub- Themes	Illustrative Extract
<p>An Episode of Change and Loss <i>The emergence of change</i> <i>Such a different person</i> <i>It affected just about everything in the house</i> <i>We were like a prisoner</i></p>	<p><i>Denise: "all that's gone so I mean it's almost like a bereavement for the child you had...which is another strange thing to say because he's here but it is in a way: it's like losing a child you had " (1353).</i></p>
<p>A Struggle to Understand <i>I wish I could understand</i> <i>It's just so frightening at the time not understanding</i> <i>Not knowing what's going to happen</i> <i>Everybody has a different opinion</i> <i>Nobody would listen</i></p>	<p><i>Anne: "What I want to understand is where does it come from; you know, can you blame the drugs or was there...is there a chemical reaction in the brain? You know and is psychosis just another type of schizophrenia" (1819).</i></p>
<p>Getting Help <i>The hardest thing we've ever had to do</i> <i>That's what I call being well looked after</i> <i>The services let you down</i> <i>We could have done with</i></p>	<p><i>Margaret: "But they came back saying the crisis team were coming. The next day, which was Sunday. Which was great. ...then someone was coming there everyday. Coming everyday" (37).</i></p>
<p>Getting Back to Normal <i>Slowly coming back</i> <i>The ingredients of recovery</i></p>	<p><i>Margaret: "I think seeing [daughter] coming out of it was a good thing, really really good at coming back to chatting and talking, slowly coming away from everything that she felt was wrong" (245).</i></p>
<p>Hope Kept us Going <i>Without hope you might as well give up</i> <i>That's where my hopes come from</i> <i>That's why I lost it</i> <i>Not hoping for anything extra special</i></p>	<p><i>Steve: "There's always got to be hope. Without hope there's not a lot of point really" (413).</i></p>

5.3 *An Episode of Change and Loss*

Caregivers experienced the young person's episode of psychosis as having brought about major change and upheaval. The onset of the young person's psychosis was characterised by caregivers beginning to notice changes in the young person's behaviour and their developing a sense that something was not right. The changes which followed the young person's psychosis were also experienced as resulting in significant loss. This loss was experienced for caregivers themselves, the young person and other family members. The young person's loss was experienced across many domains of their functioning, including losses to their character and personality, personal care and social functioning. Caregivers, through having to provide intensive and unrelenting support, experienced many losses and changes to their previous ways of life. Loss for family members included a loss of previous ways of family life, relationships and the loved one they knew.

5.3.1 *The emergence of change*

This sub-theme characterises the early experiences of caregivers in their beginning to notice changes during the onset of the young person's psychosis. Caregivers developed a sense of something being wrong through noticing differences and changes in the young person. During these early experiences, whilst sensing something was wrong, caregivers appeared confused and mystified by what was happening, unaware of what the changes signified.

Margaret: "I thought oh dear, this can't be right at all" (29).

A strong parental instinct or intuition that something was wrong was evident within a number of the interviews. This seemed to reflect caregivers having an intimate relationship with their loved one; sensing there was something seriously wrong. Also, caregivers were often certain that something was wrong despite others not sharing their concerns.

Denise: "So, it's not anything...not a big change for them, you know; whereas for us, we knew, you know that something was definitely going on" (1224).

For some caregivers the changes emerged very quickly, seemingly without warning, and represented a massive and sudden shock. Other caregivers described noticing a gradual emergence and development of change over a substantial period of time.

Denise “And um, it was just...a very gradual change in him. Hardly noticeable at first, you know just little things like sleeping longer and he...he was never ever angry or...he’s not that type of person. He’s not aggressive in any way. He never was so that...nothing changed from that point of view: he was still quite a...quite a calm person. But it was just subtle changes...” (7).

For participants describing a gradual development of change, the young person was often described as having been different since they had been much younger. Following the emergence of the psychosis, caregivers described having to quickly try and cope with the changes and provide support and care for the young person as best as they could. During the onset of the young person’s psychosis, caregivers often had to manage an acute crisis of change and began to seek help, both from within their existing support networks and directly from professional health services.

5.3.2 Such a different person

Emphasised within this theme are caregiver’s perceptions that the young person’s psychosis had resulted in significant change and losses across many domains of their functioning. This included a loss of positive aspects of their character and social functioning, regressing to a child-like state and so losing their abilities to provide for their own basic needs, and them losing control over their thoughts and behaviour. Because of these changes, caregivers described themselves and other people experiencing grief and bereavement.

Caregivers described their psychosis as resulting in the young person becoming a very different person and losing positive aspects of their previous way of life.

Denise: “It’s awful because...sorry <speaks softly>. [son] before was such a different lad. He had so many friends. He was well liked. He had so many hobbies. He was a real active, outgoing lad. Caring – I mean he’s still caring, don’t get me wrong, that’s not changed. Um, but

he was just such a different person. Now he seems to be a very...very unhappy really” (253).

Caregivers described transformations to the young person’s character and personality, and a loss of social functioning was also described whereby the young person had lost friends and become very isolated as a result of their psychosis. Caregivers often perceived the young person as having lost their ability to look after themselves and regressing to a child-like state. The consequence of this seemed to be that the young person became entirely dependent on their caregivers.

Denise: “it’s like having a small child again, you know when we should have a grown lad, who should be independent, you know we’re having to look after him again” (1365).

Caregivers also described the young person as being unable to provide for their own basic needs.

Steve: “Because he won’t eat; if you leave him on his own, you can go home...I can go out in the morning and come back at tea time and he’s either not bothered getting up or he’s not bothered having ought to eat” (251).

As a result of their disturbed thoughts and behaviour, caregivers also described the young person as having lost their self-control, often seeming to be in denial or having lost insight into their having mental health difficulties.

Denise: “he actually jumped in the pond you know it was just...couldn’t settle him at all. He wouldn’t...we were trying to say him: ‘Just go to bed;’ but he was literally like a monkey climbing up the walls and you know sort of trying to climb sideways; on and off his bed, and up the stairs, down the stairs, you know” (216).

Having experienced the young person change in so many ways, caregivers described experiencing loss and bereavement of the loved one they knew.

Denise: “all that’s gone so I mean it’s almost like a bereavement for the child you had...which is another strange thing to say because he’s here but it is in a way: it’s like losing a child you had “ (1353).

5.3.3 *It affected just about everything in the house*

This sub-theme relates to caregiver's descriptions of how the young person's psychosis had affected family members and family life generally. Psychosis was described as causing significant changes to family relationships. Whilst these changes were often negative, some positive changes were also described. Caregivers described family relationships changing as a consequence of the young person's psychosis, often resulting in a sense of loss and bereavement for other family members. Following the young person's psychosis, caregiver's also described major changes and loss in their marital relationships.

Anne: "You know our marriage has just been completely blown out of the way" (1506).

Whilst describing a range of negative relationship changes, caregivers also described positive changes in family relationships following the young person's psychosis, including changes to their marital relationships.

Carol: "his illness, cause our relationship changed as well with my husband, for the better" (865).

Caregivers described the young person's psychosis as having caused massive disruption to every aspect of family life. Going further than suggesting the young person's psychosis had simply disrupted family life, for others psychosis had completely destroyed their family.

Anne "And it's like somebody put a bomb in the middle of my family" (477).

5.3.4 *We were like a prisoner*

This sub-theme relates to the practical and physical constraints placed on caregivers as a result of the young person's psychosis. Caregivers described finding their care role as extremely restrictive. For some caregivers, the restrictions placed upon them were expressed in much stronger terms, suggesting that their lives had been irrevocably damaged and they were now experiencing a very different and surreal existence:

Anne: "He's destroyed my life...well he's not destroying it, he's destroyed it (590); "you don't know what normality is any more. You just feel like you're in a nightmare" (751).

Caregivers also described losing their own sense of identity and sense of self, seemingly because of the limits and constraints of their care role.

Anne: "You become so trodden down with it all you forget who you are as a person...you know. You're no longer an individual. You're just somebody's mum who's got psychosis." (1059).

Caregivers were also required to provide unrelenting care and often expressed not wanting to leave the young person on their own. Due to the unrelenting care they were required to provide and the demands involved, caregivers described finding their care role as extremely tiring. Needing to be flexible in providing care was also described whereby carers were unable to plan ahead and needed to be available at all times, often requiring them to change their working arrangements.

Steve: "So what I tend to do was I would work when [son] was asleep. Um, and work whatever hours (242); "So I had to tell people I just couldn't work anymore...so since I have done all my work from home really (309).

Having to manage and support the young person with their distress and disturbed behaviour was also cited as a major difficulty. Some caregivers also described having to be very careful what they said and how they behaved near the young person. Caregivers described coping with the constraints of being a caregiver by having a life and activities separate from their care role.

Steve: "So the only thing that really helps me is to go and do something different. Erm, and to almost have two lives; one where I'm with [son] and one where I'm not and to not let the two cross" (285).

5.4.0 A Struggle to Understand

A major challenge and difficulty within the experiences of caregivers was not understanding what was happening to the young person. Caregivers appeared desperate for a way to understand and make sense of what was happening. During the onset of the young person's psychosis, caregivers were bewildered by what was happening and formulated a range of possible explanations. Not understanding

what was happening appeared instrumental in the emotional distress that caregivers experienced. Having no prior experience of caring for someone with psychosis and having little knowledge about psychosis meant that caregivers faced an uncertain future. A lack of a shared understanding within the family often led to family members disagreeing about what they should do to help the young person and also blaming one another for what had happened. Caregivers also described experiencing difficulty with not being listened to or understood both by other family members and mental health services.

5.4.1 I wish I could understand

Caregivers were bewildered and confused by what was happening to the young person, and expressed a desperate need to understand.

Denise: "I do wonder how he feels though. I wish I knew...you know I wish I knew what was going on in his head: obviously there was a lot of stuff going on in there when he couldn't focus. I wish I could understand that a bit more...if you search on the internet there's all sorts but it doesn't actually tell you, does it? You know you can't imagine what it's really like for him. I think if we could understand that more then it would be easier to understand the way he is." (1377).

In trying to understand the changes during the onset of the young person's psychosis, caregivers made various lay attempts to explain what these changes possibly meant.

Denise: "Up until then really we...it just seemed like some sort of depression or, you know laziness basically. You know we didn't...didn't quite know what was wrong with him. And it's not something that you expect you know! Your...your son who's been perfectly healthy and, you know happy..." (115).

In trying to make sense of what was happening, participants often described a context of stressful life events and family difficulties as implicated in the changes they were noticing.

Carol: "we were having a lot of problems..my husband, at the time" (70).

Susan suggested that her daughter being the eldest child and the increased pressure that this involved may have been causally implicated in her psychosis. Caregivers were also confused by what psychosis actually is and what had caused their loved one to become psychotic. Not understanding what psychosis was made it difficult for caregivers to look after the young person.

Margaret: "I didn't know what a psychotic episode was. I couldn't protect [daughter] because I didn't know what I was protecting her from." (59)

Other family members were also described as being confused and mystified by what was happening, and needing a way of understanding. In order to address their confusion and lack of understanding, caregivers often began to search for information themselves and also described needing to be provided with more information about psychosis. In managing the difficulties of not understanding, having some way of attempting to understand what had happened was seen as being useful for caregivers.

Anne: "I think useful things would be a full package of the services for the parents; to explain what each service does; to explain...you know, what psychosis is, how it will affect, you know" (1449).

Caregivers also described the need for more education within schools about mental health problems and drug use.

5.4.2 It's just so frightening at the time not understanding it

Not understanding what was happening appeared instrumental in triggering a range of very difficult feelings. The emergence of psychosis was initially associated with shock and fear, intensified by caregivers not understanding what was happening.

Carol: "...the beginning was just total shock and plus the fact I didn't know anything about it..." (372).

Caregivers also described feeling very angry, this often alternating with a range of other difficult emotions. Again a lack of understanding about what was happening seems instrumental in the intensity of these feelings.

Denise: "which wasn't easy because <pauses> we didn't really know what was going on with him. So...we...I think we all went from being totally angry

with him all the time and shout and get annoyed with him, to the other side where, you know we just felt so sad and sorry. You'd swing it back and forwards all the time, but we didn't have a clue really what was actually going on in his head" (365).

Caregivers often described feeling very guilty and often to blame for what was happening. Not understanding what was happening again seemed instrumental in these feelings. Caregivers also reported family members feeling bereaved because of a lack of understanding about what had happened and reported feeling very alone and isolated, often because of other people not understanding. Other people not understanding was also described as causing difficult feelings.

Steve: "The biggest hurt is the fact that people don't understand— people not understanding" (347).

Not knowing how to care for the young person, underpinned again by a lack of understanding, was a major worry for caregivers and they appeared desperate for someone to help them and tell them what to do.

Susan: "I was that worried I didn't know what I was doing. I'd have taken any help that was given cause it was such a bad experience" (1130).

5.4.3 Not knowing what's going to happen

Caring for a young person with psychosis also involved having to manage an uncertain future. A lack of understanding and failing to have prior experience or knowledge about psychosis resonates strongly through this sub-theme. Caregivers described believing at times that the young person's psychosis may be life-long or permanent.

Margaret: "At first I thought [daughter] was never ever going to come out of this, she was going to be like that for the rest of her life" (323).

Managing uncertainty in the young person's behaviour was also described as a major challenge for caregivers.

Susan: "you don't know what's going to happen next; especially if you've never experienced...I don't know. I've never experienced anything like that..." (1146).

The uncertainty for some caregivers included thoughts and fear that the young person may commit suicide.

Anne: "I have to be there to support him because my biggest fear as a parent is: he's going to kill himself" (532).

In managing and learning to live with this uncertainty, caregivers described needing to be very flexible.

Steve: "My attitude really is just to keep on going...just take one day at a time really. That's all you can do. You can't...you can't do anymore than that" (175).

As a consequence of this uncertainty, caregivers also described finding themselves needing to be extremely vigilant and constantly checking for any changes in the young person.

Margaret: "I'm still watching. I find I'm still watching just to make sure she's alright. Erm, if I see any slight change, I was saying to her are you feeling alright, are you sure you're ok?.....But I'm watching all the time" (116).

5.4.4 Everybody has a different opinion

Caregivers described family members often disagreeing and arguing about how best to help the young person with psychosis.

Denise: "And it's not been easy, you know 'cause we've not always agreed all of us, the way to go. Everybody has a different opinion, you know as to what should be done" (1177).

In trying to make sense of what was happening, caregivers described family members often attributing blame to one another.

Carol: "I blame him [father] sometimes...it's all your fault. You did this to him...it's just finding somebody to blame" (868).

Steve described other family members placing blame on him

Steve: "I think most people in er, in my family think you've actually done something wrong. You've done it

wrong and you've got it wrong. And you continue to get it wrong" (342).

Susan also described her daughter as blaming her father for her psychosis.

Susan: "When she was ill, he was coming to see her she just said to him, this is your fault why I'm like this because...of what you've done to me...I think he just didn't like it and he swore at her and walked out and didn't come back for six months to see her..." (393).

5.4.5 Nobody would listen to me

As well as caregivers and other family members not understanding what was happening, not being listened to and understood themselves was also described as very difficult. Both Carol and Denise describe feeling frustrated by their perception that mental health services were not listening and understanding their views and concerns

Denise: "it seemed like nobody would listen to us. And we felt like um...<pauses> we weren't...our opinions weren't valued...although we knew <son> best of anyone; and also the fact that <organisation> hadn't known him before he was ill...so they were only seeing him, you know from...whereas we can compare what he was like, you know before that. And he was such a different person and we couldn't seem to get that across to them" (401).

Not being heard and understood by other family members was also described as very difficult.

Anne: "One of the hardest things is trying to get my husband and my daughters to actually understand how I feel; and to look at it from my side (766)".

5.5 Getting Help

This theme relates to the experiences of caregivers in accessing and receiving help from mental health services. Experiencing the young person being forcibly detained and admitted to a psychiatric inpatient unit was described as a particularly difficult experience. The support given by mental health services was perceived by some caregivers as very positive and a range of experiences were described to illustrate what being well looked after had meant for them. Other caregivers described a range of experiences in which mental health services had failed to provide them with support and also described a range of difficulties accessing the support they needed. Many participants appeared to have felt very alone in their role as a caregiver and described additional forms of support that would have been useful for them.

5.5.1. *The hardest thing we've ever had to do*

A number of caregivers described having experienced the young person they were caring for being detained and forcibly admitted to a psychiatric inpatient unit. Whilst desperate for help for the young person, caregivers found the experience of having their loved one detained as an extremely challenging and traumatic experience.

Anne: "Um, so we ended up having to call the police and having him arrested just to keep him safe; which is the hardest thing we've ever had to do in my life. And they kept him in the cells over the weekend and eventually got services to do an assessment on him and he was under a section and taken to hospital" (188).

Difficult experiences were also described during the young person's admission. Carol, in a similar way to Anne, wanted help for her son but found the admission process extremely difficult. Because of the young person's condition and their needing intensive treatment, she was prevented from visiting her son during the early part of his admission and experienced this as very difficult.

Carol: "They wouldn't let us see him...that was horrible" (327).

For other caregivers the young person's admission, whilst a difficult experience, was experienced as providing a sense of relief.

Denise: "...And er, when he went into hospital that was a big relief, strange as that might be" (398).

Frustration was also expressed that the admission did not happen earlier, suggesting that a much sooner admission would have prevented further deterioration.

Denise: "I think he should have been...could have gone into hospital a good year/18 months before that; and he would have, I think he would have been in a better place now if he had been..." (235).

5.5.2. That's what I call being well looked after

Caregivers described a number of experiences which meant that they had received good quality help and support from mental health services. The importance of having a quick response and consistent contact was emphasised.

Margaret: "But they came back saying the crisis team were coming. The next day, which was Sunday. Which was great. ...then someone was coming there everyday. Coming everyday" (37).

Building trusting relationships with mental health professionals was also described as important. Developing a trusting relationship with someone that the young person liked appeared to be a helpful treatment intervention for the young in itself. The building of a trusting relationship appeared to take time however, as due to their mental state the young person had been very wary and suspicious of other people. Again, the process of building such a relationship seemed a helpful intervention in itself.

Susan: [daughter] "had full trust in her [psychiatric nurse]...she really trusted her. Which came along way from how she felt the first time she met them; because she wondered what they were doing here (536)."

Other important elements of the quality of relationships built with mental health service professionals were that they understood the young person's difficulties.

Margaret: "The other person was the support worker, C, who came, C was very understanding of [daughter], she liked C and we preferred her to come than Dr B (470)".

Receiving treatment and support at home was characteristic of being provided with good quality care, although this was at times found to be quite invasive. The young person receiving home visits also provided caregivers with some reassurance that someone was with them to check on how they were and needed to know that the person visiting would let them know if there was any deterioration or concerns.

Susan: "When we had [nurse] and probably a little bit of peace of mind when I know that...like when the people from [EI service] go and visit her; if there was a problem they would say something" (1082).

Knowing what action to take in the event of a relapse in the young person's mental health was also described as important and mental health services providing caregivers with a way of understanding the young person's psychosis appeared extremely useful in terms of them making sense of what had happened. With use of a timeline, along which significant life events prior to the young person's psychosis were plotted, Margaret was able to conceptualise her daughter's psychosis as a build-up of stressful life events.

Margaret: "When you go through the life line that they [mental health professionals] do, they went back to July and the other day I was just thinking....so [daughter] was under quite a lot of stress, from a lot of places. Erm, when you hear all the stress, it builds up" (77).

5.5.3. The services let you down

Caregivers described a number of experiences which led them to be critical of the service they received and judged services as having failed to help them. Some caregivers were generally very critical in describing the failure of services to provide support.

Anne: "But the hardest part of it all is I feel that the services let you down" (278).

Denise described her frustrations that despite her plea for help, mental health services weren't able to do anything because her son was not presenting any major risk and was not asking for help.

Denise: "When we were really asking for help (at the end of last year...beginning of this) they just...their hands were tied by the fact that they couldn't actually do anything until <son> either went over the top, or did something to either hurt himself or someone else. Or, I don't know <sighs> whether he'd have to go completely crazy, I suppose. That's what they were saying. And, until he did that or said himself, 'Yes, I need help,' they couldn't do anything so at that time I felt that we were just on our own. It was just a case of go home and get on with it..." (351).

Experiencing a delay when they were initially trying to get help also led caregivers to view services as having failed to help them.

Carol: "we took him to a&e...they weren't interested....there's nothing we can do" (267).

Because of services failing to provide them with support eventually led Anne deciding not to bother contacting them anymore.

Anne: "Well, I'm not going to bother calling them because they're a waste of bloody time" (301).

Caregivers also described difficulties attending appointments as they involved coming into contact with other mental health service users for the first time. Having no consistency in the professionals they met in the appointments meant that they were required to explain again what had happened and re-visit the history of the young person's problems.

Susan: "They were quite stressful were the appointments....because you didn't know who you were going to meet in the waiting room...they were frightening. I'd never come across people like that" (406).

Anne described her difficulties with having to take annual leave from her work in order to attend appointments and only being able to contact services during working hours.

Anne: "But, unfortunately, within the NHS it's not always easy to get, you know, keep making you take annual leave, which I think is unfair..you know, so I do

struggle with that now...and because I'm working the hours I work, I can't even contact anybody from [EI services] because I'm at work. When I get home from work, they're gone" (716).

Because of services not being available outside of normal working hours, caregivers described feeling very alone.

Anne:" I think as a parent you feel very, very alone...you know. Okay, you've got [EI service], you can ring them during the day but only till five at night. And you know damn well after five at night and on a weekend, you're stuffed. You know you've had it! There's nobody there and that is frustrating" (415).

5.5.4. We could of done with

In describing their experiences of getting help from mental health services, caregivers identified a range of additional forms of support which would have been useful for them. Caregivers appeared to feel very alone and unsupported, and the additional support they described reflected a need for services to address this. Caregivers expressed wanting mental health services to be able to do more, but at the same time recognising the limitations of what was possible.

Denise: "So I mean we could have done with...I can't really say more support, but...<pauses> for them to have the means to do more; whereas they didn't seem like they could do it. I think they would have done if they could, but they just could not do it, you know" (1227).

Needing guidance and emotional support outside of normal working hours during times of crisis or difficult situations was also described.

Anne: "May be somebody to talk to on a night. You know when things have been bad and you've got him settled; and it's then the quiet...what I call the quiet time. But you find when it's all blown up and then calmed down, that's the time, that as a parent, you need somebody" (1035).

Caregivers described wanting respite care from professionals who they could trust and were able to look after the young person in a way which they perceived was appropriate.

Steve: "I would like someone I can leave him with. Without feeling he'd been left with somebody...so I suppose it's going to be support from somebody who's gonna look after him" (721).

When a young person was refusing to take their medication, caregivers described wanting services to be able to intervene with use of a treatment order.

Anne: "I also think what they should have is like...like [son] is not taking his medication again. Oh, he won't take it. And he's like spiralling out of control again. And I think when they can't be trusted, slap a treatment order on them" (1833).

Needing to share their experiences with other caregivers was also described.

Denise: "You want to share, you know your experience with someone who may be experienced it" (804).

Margaret and her husband were offered the opportunity to access such support groups and, whilst viewing these as useful, but did not perceive their having the need to access these. Denise, however, described such support groups as unhelpful for her as she was able to access such support from within their family and wanted instead immediate action to be taken to help her son.

Denise: "I know they had some support groups with other parents. I don't know if that would have helped us at that time...because again you would only have discussed what was happening. It wouldn't have improved it. It would have got it off your chest...but as a family, we could do that anyway..." (1254).

5.6. Getting back to normal

This theme relates to the experiences of caregivers during the recovery process. The young person's recovery was characterised by a sense of 'getting back to normal' and the person caregivers knew before their psychosis slowly returning. A sub-theme emerged which relates to the experiences of caregivers during the recovery process and the signs which they described as indicating that their recovery was taking place. A second sub-theme relates to descriptions by caregivers of factors which constituted and facilitated their recovery.

5.6.1 Slowly coming back

Caregivers described a range of experiences during the young person's recovery. This was characterised by the young person they had known before the episode of psychosis slowly returning, and seeing gradual signs of this happening was described as very positive. Margaret's description below indicates that seeing her daughters recovery was experienced almost as a gradual re-union with the daughter she had, leaving behind what had been wrong during her episode.

Margaret: "I think seeing [daughter] coming out of it was a good thing, really really good at coming back to chatting and talking, slowly coming away from everything that she felt was wrong" (245).

The young person becoming interested in certain things which they had liked prior to their FEP was seen as indicative of them recovering and their previous ways of being returning.

Susan: "Oh, the old [daughter] wouldn't have worn that. Then the other day she said to me, I think that old [daughter] is coming back because she would wear that. And things like that, you know, you think: ooh, she's thinking differently on different lines" (1371).

The young person's recovery process was often experienced as long and slow, occurring over many years. Although even after such a long time, caregivers appeared to suggest that their recovery was still incomplete.

Susan: "But it's like three and a half years down the line and she's got a...lot better, a lot better" (838).

For some caregivers a slow recovery was viewed as positive, perhaps allowing themselves as well as the young person to come to terms with what had happened and adjust accordingly. This may also reflect caregiver's being cautious and worried about subsequent relapse and needing to gradually build-up confidence.

Margaret: "And it was slow, but that's good. I think it's far better if it's slow" (172).

5.6.2 *The ingredients of recovery*

Caregivers described a range of experiences which they perceived as being important within the young person's recovery. Living within a normal environment whilst other people continued to do their usual everyday activities was described as important in encouraging the young person to begin to do more and more.

Susan: "...but try to live a normal life round her made her may be come out of herself a little bit; and then she had to do things a little bit more for herself" (1318).

In getting back into everyday life, a general emphasis was also placed on the young person just doing things.

Margaret: "at least she's doing something...she's getting back into the swing of thing, getting back into her stride" (335).

Medication was often seen as an important stepping stone in the young person's recovery, particularly in helping the young person begin to concentrate and think more clearly.

Denise: "there are still some positive things come out from this year; and that...the medication seems to have helped him think clearer; 'cause I don't think...he couldn't concentrate on anything" (289).

Given the importance which caregivers attached to the medication, the young person refusing to take their medication often became the subject of tension and disagreement. In the description below, Margaret appears adamant that her daughter will take her medication as if her future health depends on it.

Margaret: "[daughter] would say I'm not going to take the tablet. I said you're going to take the tablet if it's

the last thing you do. You're going to take the tablet"
(176).

The young person taking responsibility for their own health and learning to look after themselves was also described. Recognising the young person's role in their own recovery appears an important realisation for caregivers.

Carol: "It's controllable from what I've learnt. It's...if he learns to manage and control himself (848).

The young person having a self-determined character was also described as important in the young person progressing in their recovery.

Susan: "probably the only way she's come so far is because she's very determined and that it wasn't going to, you know take over her life" (690).

For Susan's daughter, going back to work as soon as she could was seen almost as another part of her recovery. Having the opportunity to mix socially with other people was also described as being facilitative of recovery. Susan suggests that her daughter's difficult thoughts had been challenged and had developed a very different outlook through an unpleasant social experience.

Susan:" Well her thoughts have gone! But it was through a not very nice situation with someone she knew (the man that she'd put trust in who she used to work with)...and so it made her start thinking about that; and it took the thoughts away. Just like that" (600).

Providing frequent encouragement was also described as well as becoming less involved and allowing the young person to have space. The adjusting and learning to become less involved was described as difficult, however.

Anne: "I've had to pull back and say right, get a check on this because while you're being the way you are with him you're not doing him any favours...as a mother that's been very difficult for me. Because I am by nature a very loving person" (548).

5.8. Hope Kept us Going

This theme relates to caregivers descriptions of the importance of hope within their experiences. Hope was generally seen as essential by caregivers in them coping with the many challenges and struggles they faced and as a motivational force for the recovery process. A range of experiences were described which were perceived as strengthening and weakening levels of hope. Within caregivers accounts there appeared an adjustment in their hopes for the young person towards them simply being well and happy. This appeared to serve a protective function against disappointment and further loss.

5.8.1 Without hope you might as well give up

Caregivers described hope as essential in them continuing their efforts as caregivers and as a critical motivating force. This suggests that without hope caregivers would have struggled with the major challenges and difficulties previously described. Denise suggests she would have been unable to carry on as a carer without believing that her son would improve.

Denise: "...if you don't have some sort of hope and um, belief that things are going to improve then you might as well just give up..." (698).

Similarly, Steve describes his sense of hope as continually motivating him in providing care, without which his role as a caregiver would have no purpose.

Steve: "There's always got to be hope. Without hope there's not a lot of point really" (413).

Denise described her sense of hope and being positive as important in both herself and others continuing to support her son, suggesting that without her and her family remaining positive external people such as mental health services may also decide to stop trying.

Denise: "...trying to be positive. I always try and think, 'well, things are getting better.' <Pauses> and you can't give in really. And that...that's what keeps me going. In fact that...you know <pauses> if I stop working on <son> then, you know everybody else will think it's not worth it either. You know, if

we as a family decided to give in then who else is going to bother?" (882).

Anne suggests that her hope was essential in her coping with the daily challenges of her caring for her son.

Anne: "You're just going from each day hoping to God that you're going to get through it" (1467).

In terms of the nature and focus of the hopes held by caregivers, both general and specific hopes were described. Steve expressed general hope that he and his son would be able to maintain their current lifestyle.

Steve: "But not hope for a specific thing. Hope that we go somewhere and we get somewhere and that we both carry on doing it really, I suppose, that's the only hope er, but no, no ambitions" (413).

Other caregivers expressed more specific hopes. In terms of recovery, Anne described her hopes as being that her son's admission to hospital would provide him with the treatment he needed.

Anne: ".it's like anything, when somebody goes into hospital you hope that they go in; they get better and they get the help they need" (946).

Susan describes her specific hopes being that her daughter's recovery would continue and that she will be able to lead a fulfilling life, without psychosis returning into her life.

Susan: "Well, I hope she can carry on the way she is. And I hope she leads a normal life. The best she can. You know that it doesn't rear its ugly head again. If they start weaning her off the medication, I hope it doesn't come back (984).

5.8.2 That's where my hope comes from

Within caregiver's experiences, many sources of hope were described, these included: observing positive changes in the young person during their recovery, family relationships, making positive plans for the future, the help received from mental health services and the relationships formed with mental health professionals, being within hopeful relationships with others, thinking of people in

worse situations, hearing positive outcome stories, understanding what had happened to the young person and a belief in positive aspects of the young person's character.

Denise describes very small signs of improvement in her son as providing her with a sense of hope. She acknowledges that for other parents these signs might indicate a problem rather than be viewed positively.

Denise: "I mean the little things are giving us hope even now; the fact that he can get up! <Chuckles> you know if he has to get up for something, he can get up. Whereas before, he just couldn't so I mean it's...it's really little things where I'm sure people with kids of his age would think, 'there's something wrong with that kid,' you know! They're happy that he's managed to do this one thing but for us it's a big thing because he wouldn't do it before.....you know. So really, for me it would be a glimmer of hope that he did actually start to focus on doing something rather than...just being in bed". (583)

Steve described seeing signs of his son's behaviour changing as providing him with hope.

Steve: "There's hope in that...there's hope in the fact that he's changing (391).

Denise describes the improvements following her son beginning his anti-psychotic medication as also providing her with hope.

Denise: "I definitely see now some changes since he's been on the medication that gives some hope but as we go forward" (477).

Hope was also described as developing through the interactions between family members and the young person, and being hopeful and positive was seen as being critical in the young person themselves and other people continuing to remain positive and supportive of the young person recovering.

Denise: "you've just got to be positive all the time. Never give in...because that...I think that passes on to them [son] as well, you know if you start speaking negatively

to them, then it, you know it's like a wave that washes over everybody" (922).

Hearing positive outcome stories about other young people with psychosis was described as providing a greater sense of hope. Susan described hearing about another young person who had experienced similar difficulties to her daughter as giving her a sense of hope that she would improve.

Susan: "And I thought, well may be if he's been that ill and he can walk into a supermarket now and he can do shopping and things like that. May be there is hope" (762).

Margaret also reflected on hearing such stories from her daughter's mental health support worker as important in giving her a sense of hope.

Margaret: "When you see that people can come out of these episodes and that they can live a normal life, and alright it may take a while (333).

Being aware of other people in worse situations was also described as important for the young person being hopeful.

Susan: "Then she starts thinking of other people...there is people worse than I am" (1070).

The process of planning for the future and the young person developing a sense that they are still capable of pursuing their ambitions also appeared to confer a sense of hope.

Carol: "He's got more hopes now that he can actually go back to university; and he can, you know lead a normal life" (531).

Developing trusting relationships with mental health professionals who the young person liked was described as providing hope for the young person.

Carol: "And then now he sees [ei worker]...he really likes and he trusts him and i think thats helping a lot; and I think hes got more hopes..."(533)

Mental health professionals highlighting improvements in the young person's condition was also identified as providing hope for the young person.

Susan: When she goes to see the doctor and if they tell her something that's positive, that keeps...that kind of keeps her going (1059).

Having a way of understanding the young person's psychosis also seemed to provide hope for caregivers.

Margaret: "The mind is just not thinking straight, it's jumbled, that was a great help." (330).

The young person's personality was also described as another important source of the caregiver's sense of hope. Denise described her hopes being attached to how her son was as a person before his episode of psychosis, and that the positive aspects of his character remained.

Denise: "I still think that the basic <son> is still there and that's where my hope comes from because he...he was such a positive person himself and he was a real outgoing person" (735).

Susan described her sense of hope as being based on her daughter having a strong and determined character.

Susan: "She's strong; she's very determined" (1384).

5.8.3 That's why I lost it

Caregivers described a range of experiences which led to them losing their sense of hope, these included: mental health services failing to provide support, the young person not wanting to make any changes in their life, worries about the young person's future care, caregivers continuing not to understand what had happened and hearing negative outcome stories about other people with psychosis.

Anne, particularly, described having completely lost her sense of hope. Anne attributed her loss of hope to mental health services having failed to provide her with support and suggested that for her hopes to be re-built services would need to change.

Anne: "How the hell is [son] going to get better? You know, how can it...somebody get better? You know if the services don't change then how do you move on."(1555)

Anne also described her losing hope because she does not believe that any hopes she had were achievable and her son not wanting to make any change in his life. Worrying about the future appeared to also challenge caregiver's sense of hope.

Denise: "If he stays as he is now, then he'll still be in that bedroom in bed all day when he's 30! And that's what

scares me: the thing that really, really worries me. You know that he won't move on from this" (1079).

Needing to make plans for the young person's future care also seemed important in caregivers not losing hope. Not understanding what had happened and continuing to be confused and bewildered as to why the young person had developed psychosis appeared to challenge caregivers' sense of hope.

Carol: "I mean I'm hopeful...I'm getting better but there's still a lot of unanswered questions up there" (772).

Anne described thinking about other family members who had had long-term mental health problems as lowering her sense of hope for her son.

Anne: "I think that my cousin was schizophrenic, that doesn't give you a lot of hope (969).

5.8.4 Not hoping for anything extra special

Within caregiver's descriptions of their hopes, an adjustment of their aspirations for the young person was evident. Hopes tended to focus on more basic goals such as them being happy, active and able to live a normal life.

Carol: "...have an education, hopefully or if not, get a job; just normal things. You know I don't want anything extra special. I don't want <pauses> don't have high expectations. I just want him to be happy because I think he's <begins to cry> been through a lot of unhappiness through all of this" (465).

Margaret described simply wanting her daughter to be well and able to enjoy life.

Margaret: "For me, as long as [daughter] is alright, that's all I ask. It's not a lot out of life, but it has to be enjoyed" (354).

This adjustment in caregiver's hopes appeared to function as a defence against disappointment and failure. Within Denise's description below she also describes being externally very hopeful for the benefit of her son, but internally cautious and reserved.

Denise: "But it definitely isn't easy! We've had quite a few knocks like that. But now when, like I said to you before, when he says he's going to maybe do something...outwardly to him I'm completely positive; but I

do keep a little bit of reserve...you know thinking, 'this might not happen. So don't get too...' you know, 'don't get too excited by this because...' you know, 'it's...you might be disappointed.' ...but um, <pauses> like I say, with him I would be completely with him, you know whatever he decides to do ...but I think, you learn to hold back a little bit inside. Not necessarily showing it to him...just...I think you have to do that for your own <pauses> protection really; or else you'd just be a complete wreck! (1008).

6.0 DISCUSSION

The aims of the present study were to address two major research questions: What are the experiences of primary caregivers of young people experiencing FEP involved with an EI service? In what ways does hope feature within the experiences of primary caregivers? In order to address these questions, the following section will outline the main research findings and links with the extant literature will be made throughout. This is followed by an evaluation of the research methodology. Lastly, potential clinical implications of the research findings are then outlined.

6.1 Change and Loss

The theme *an episode of change and loss* identified within the present study suggests that caregivers experienced significant and distressing upheaval and bereavement following the onset of the young person's psychosis. As reported in previous studies (e.g. Schene, Wijngaarden and Maarten, 1998), caregivers experienced the emergence of the young person's psychosis as triggering a range of difficult feelings and emotional distress including fear, shock, anger, worry, sadness, guilt and grief. The findings of the present study are supported by previous studies which suggest that families experiencing a first episode of psychosis endure high levels of distress due to changes in the young person emerging acutely and without warning, the lack of prior experience and the uncertainty as to what these changes might signify (Addington, Collins, McCleery & Addington, 2005).

Participants provided a very detailed chronology of events leading up to and during the onset of the young person's psychosis, signifying this as an unforgettable experience, following which their lives and those of their family became very different. Caregivers described both a sudden and gradual emergence of change and were mystified by what these changes signified and how they should respond. They quickly developed a sense that something was wrong, reflecting a parental intuition and intimacy with the young person. This intuition led caregivers in beginning to seek help, although a delay was experienced by some caregivers in accessing appropriate help from mental health services.

Psychosis was described as having had a devastating impact on the young person, this often being characterised by them becoming a very different person. Caregivers were faced with having to manage acute crises in the young person's behaviour which was often very distressing. Caregivers also described extensive losses for the young person in terms of them having lost positive aspects of their character, their social networks and their ability to look after themselves. As reported in previous studies (Tuck et al, 1997), caregivers perceived the young person as having regressed to a child-like state, requiring them to return to a much earlier stage of parenting: providing for their basic needs and supporting them to do everyday activities such as going out and shopping.

That caregivers were required to provide levels of care characteristic of a much younger child, returning parents to a much earlier stage of parenting, may have implications for understanding the development of high levels of EE, particularly EOI, within families of a relative with psychosis. Whilst high levels of EE have been identified as causing poorer long-term outcomes and relapse (Jackson & Iqbal, 2000), the mechanisms for the development of EE are unclear. Some studies have suggested that high levels of EE, particularly critical comments and hostility, may be due to family members making attributions that the person with psychosis has control over their behaviour and experiences (Patterson, 2005). Other studies suggest that first episode caregivers displaying high levels of EE tend to appraise their situation as more stressful (e.g. Raune, Kuipers & Bebbington, 2004). Patterson (2005) found high correlations between emotional over-involvement (EOI) and perceptions of loss in family members of a relative experiencing FEP, speculating that EOI may represent an adaptive response by family members to recover their perceived loss. By providing an in-depth exploration into the experiences of caregivers, the findings of the present study provide an alternative way of understanding the development of EE.

Within the present study caregivers described having to look after a much younger child and them having to parent them as such. Caregivers in the present study described returning to a much earlier child-parent relationship, meaning that they became more involved with the young person such as reminding them to look after their basic needs and supporting them with everyday activities. As well as practical aspects of caring, carers also had to become more involved at an emotional level such as offering guidance and modelling emotional regulation.

Given their fears, after recovery from the first episode, that relapse may occur and perhaps feeling to blame for what has happened, it may be difficult for caregivers to relinquish this level of involvement, therefore perhaps creating a family context where emotional over-involvement and over-protection could develop.

Previous research suggests that a greater duration and severity of psychosis often results in a greater impact on family members (Addington et al, 2003), and the experiences of Denise and Anne would appear to support this. Both Denise and Anne had experienced many years of caring for a young person with psychosis, which had led to themselves and their family experiencing times of overwhelming distress and helplessness. For all caregivers, the young person's psychosis was described as causing a marked upheaval within the family household; introducing a very different way of life which they and their family had struggled to cope with. Having to provide extensive and unrelenting care meant that caregivers often found their care role as incredibly tiring and exhausting. As reported in previous studies (Tuck et al, 1997) caregivers often perceived no end to their care providing, seeing it as a life-long responsibility. The restrictions and constraints placed on caregivers led to a perception that they had lost their personal identities, becoming personally defined by their care role.

As has been reported in previous studies (Nystrom & Svensson, 2004), caregivers experienced changes to the young person as leading to family relationships becoming very different, resulting in feelings of loss and bereavement. This loss often seemed intangible as the young person, whilst perceived as very different, was still present. Whilst the experience of relationship loss and bereavement following psychosis has been well documented, positive change following psychosis has received less coverage within the literature. In the present study, caregivers reported relationships with the young person as having become much closer, characterised by family members spending more time with the young person, improved communication and emotional warmth. Similar changes were described by McCann, Lubman & Clark (2009) in their interviews with Australian caregivers of a young person FEP. This study reported the increased closeness in relationships with the young person as an unanticipated reward of care giving, suggesting that caring for a young person with FEP is not solely burdensome (McCann, Lubman & Clark, 2009) but can have a therapeutic effect on the family system.

The present study also suggests that relationship growth and development is not limited to relationships with the young person. Relationship development also occurred within the wider family system. For instance, Carol described her marital relationship as having become much closer and less acrimonious following her son's psychosis. Whilst this was also perceived as a positive outcome following the young person's psychosis, regret was expressed that these changes had followed such a traumatic experience. In making sense of such relationship changes, systemic approaches suggest that psychosis, rather than being an expression of difficulties within the individual, is an expression of problems within the relational context, such as family interaction patterns (e.g. Bertrando, 2006). This may suggest that change and adjustment within family relationships, as reported within the present study, are often integral processes within recovery from psychosis.

6.2 The Need to Understand

In a similar way to people experiencing psychosis struggling to make sense of their experiences and to find meaning (Perry, Taylor & Shaw, 2007), the present study suggests that caregivers experience a very similar struggle. Caregivers within the present study were bewildered by what was happening to the young person and appeared desperate to understand. Not understanding what was happening made it difficult for caregivers to know how to care for the young person and how they should respond. In order to gain information and guidance on what they should do, some caregivers described searching on the internet for information and expressed a need for mental health services to provide more information about psychosis and the help available to them as well as providing guidance as to what they should do to support the young person.

As well as caregivers themselves experiencing difficulty not understanding what was happening, people outside of the family not understanding was also described as difficult. This lack of understanding often led to caregivers feeling alone and socially isolated. As reported in previous studies (Barker, Lavender and Morant, 2001), as a result of their circumstances, caregivers often described experiencing social stigma and a distancing from their social networks. To address a perceived lack of understanding, some caregivers also stated that more education relating to mental health problems should be done within schools.

A range of explanations were used by caregivers to make sense of changes during the initial onset of the young person's psychosis. These explanations conceptualised early changes in the young person as possibly indicating normal adolescent behaviour, depression or laziness. Such explanations imply that the young person has a degree of control over their behaviour, and these initial interpretations often meant that caregivers and family members became angry and critical towards the young person. This finding relates to research literature on EE, which suggests that family members believing that a relative's condition is within their control can often lead to negative affective and behavioral responses such as critical comments and hostility (McNab, Haslam & Burnett, 2007). The experiences of caregivers described within the present study may indicate that a context for EE, particularly critical comments, may develop following a FEP as family members continue to hold beliefs that the young person is in control of their behavior.

Caregivers also attempted to make sense of what had caused the emergence of the young person's psychosis. These explanations made reference to the break-down of personal relationships and a history of family difficulties. One caregiver also suggested that her daughter being the eldest child meant that she experienced increased pressure to succeed. Interviews by Barker et al (2001) also report caregivers seeking to explain the emergence of the young person's psychosis. Within this study relatives described the family member's psychosis as seeming to develop following difficult life events, particularly changes within interpersonal relationships. Also similar to the present study, during the initial onset, relatives often misinterpreted changes in the young person's behaviour as normal adolescent behavior. Signifying the importance of how caregivers make sense of the young person's behavior, Barker et al (2001) reported that caregivers interpreting changes as normal adolescent behavior led to a delay in seeking help.

Whilst many studies have reported on the types and severity of distress endured by caregivers (e.g. Addington, Coldham, Jones and Addington, 2003), the present study provides an insight into the specific experiences which may be causal of this distress. The present study suggests that caregivers not understanding what is happening to the young person is instrumental in the levels of distress they experience. Fortune, Smith and Garvey (2005) report that the understanding caregivers have about their relative's psychosis can often determine the levels of distress they experience. For example, viewing a relative's psychosis as chronic

and having stronger views about the severity of its consequences can lead to greater levels of distress. However, caregivers interviewed in the present study described feeling completely bewildered by what was happening, this may suggest that the distress experienced by caregivers during the early stages of a first episode of psychosis may be causally related to them facing such high degrees of uncertainty as to what the changes may mean and them having no understanding at all. This indicates a need for caregivers, from a very early stage, to be supported in making sense of changes in the young person, what this may mean for the young person and their family, and be given guidance on what actions they should take in supporting and looking after the young person.

The desperate need expressed by caregivers to make sense of the young person's psychosis and the significant change and loss they experienced relates to the general literature on sense-making. According to Janoff-Bulman and Yopyk's (2004) theory, when adverse life events occur which do not fit with a person's existing assumptions about the world and they are unable to make sense of what has happened, a sense of meaninglessness may ensue which can often lead to profound distress. In order to restore meaning, individuals seek an explanation for what has happened. Janoff-Bulman and Yopyk distinguish between two meaning making processes: meaning-as-comprehensibility (sense making) and meaning-as-significance (benefit finding). Meaning-as-comprehensibility involves the development of new world views or via modifying existing world views so that events can be understood. The development of a new world view may also lead to a personal growth, whereby an individual finds personal significance in their experiences (Janoff-Bulman and Yopyk's, 2004). A number of studies suggest that sense making is associated with better adjustment and coping in parents with children with a range of conditions such as chronic illness and disability (Pakenham, 2007). Caregivers within the present study demonstrated a desperate need to make sense of what had happened, and this existing literature suggests that caregivers making sense out of the young person's psychosis is important in resolving their distress and to them adjusting and coping more adaptively.

The sub-theme *not knowing what's going to happen* characterised the experiences of caregivers in having to manage an uncertain future. Faced with such high levels of uncertainty further increased the emotional distress of caregivers. The uncertainty faced included beliefs that the young person's psychosis might be

permanent, the young person experiencing fluctuating levels of distress and need, and fear that they may attempt to commit suicide or seriously harm themselves. This uncertainty meant that caregivers needed to be extremely flexible and continually vigilant for signs of change. Research by McCann et al (2009) identified a very similar theme; this was termed *Roller Coaster and Unpredictable Experience*. Caregivers interviewed within their research described difficulties with managing unpredictable fluctuations in the behaviour of the young adult with psychosis, which meant fluctuating demands were placed on caregivers, alternating between times of relative calm and times of intense care giving.

Caregivers within the present study also described family members holding different views about the young person's psychosis and how they should look after them, often leading to family tension and disagreements. Reflecting a need to understand what had happened to the young person, family members often blamed each other for what had happened. It would seem evident that such experiences compounded the challenges faced by caregivers and increased the emotional distress within their families. Caregivers also expressed difficulties with their views not being listened to and understood both by other family members and mental health service providers. This indicates a need for all family members to be supported by service providers from a very early stage to share their views with one another and to form a shared understanding of the young person's psychosis. To prevent blaming within families and the distress this is likely to cause, there would also seem to be a need for families to be sensitively supported in forming a shared understanding. Rather than simply providing families with standardised information, caregivers should be supported in this process through dialogue and the sensitive provision of information which can be incorporated within their existing knowledge and lay understandings.

Such interventions in supporting family members to make sense of the young person's psychosis and its likely cause would appear very similar to the Open Dialogue approach practiced in Finland (Seikkula & Olson, 2003). Within this approach the young person's social network including friends and family are regularly brought together by mental health professionals immediately following a young person's psychosis to share their views on what has happened, express their concerns and to formulate a shared understanding through dialogue. This intervention has been demonstrated to have very positive clinical outcomes

(Seikkula & Olson, 2003) and would appear to be well suited in meeting the needs of caregivers to develop a shared understanding of what has happened from a very early stage of the young person's psychosis.

6.3 Accessing Help

A range of experiences were described by caregivers relating to accessing and receiving help from mental health services. Three caregivers experienced the young person whom they were caring for being detained and forcibly admitted into psychiatric care under a mental health act section. Whilst caregivers were in support of the admission, they described this as a very traumatic and distressing experience; *the hardest thing we've ever had to do*. Witnessing the young person in a highly distressed state, needing to be restrained was described as very upsetting. Within caregivers accounts of the young person's admission there was also a sense of them believing they had failed the young person. Following admission caregivers were often not allowed contact with the young person for a period of time, and this was also experienced as very difficult. Such challenging experiences indicate a need for caregivers to be supported throughout the process of admission. Services providers should be sensitive to the trauma which admission often causes for families and provide opportunities for caregivers to explore their concerns and the difficult feelings triggered. For one caregiver however, the young person's admission was described as providing her and her family with a strange sense of relief and they also expressed frustration that the admission had not happened sooner. This relief and frustration appeared to have followed many months of providing care and a long history of repeated requests for help and intervention.

Caregivers also described a range of experiences in receiving help from community health services. Some caregivers described the help they received very positively, whereas other caregivers were very critical and described a range of shortcomings in the service they received. Within the sub-theme *that's what I call being well looked after* caregivers described a range of positive experiences in receiving help and support, these experiences included: having received a quick response from services during the onset of the young person's psychosis; regular and consistent contact with professionals from the crisis service and EI team; professionals visiting the young person at home and the young person not being

admitted to hospital; caregivers being aware of what action to take in the event of a deterioration in the young person's mental health; building trusting relationships with professionals whom they liked and were perceived as understanding the difficulties of the young person; and professionals providing information about psychosis and supporting them in making sense of what had happened. Such positive experiences reflect positively on the two EI services from where participants were recruited, and indicate that for many of the caregivers interviewed within the present study, the aims and objectives for early intervention in psychosis such as reducing treatment delay, improving access to services, engaging with families, providing flexible community care rather than restrictive inpatient care. (Bertolote & McGorry, 2000), had been delivered and had resulted in positive clinical outcomes.

Within the sub-theme *the services let you down*, caregivers described community health services as having failed to respond during the onset of the young person's psychosis, expressed frustration that services did not intervene sooner, and reported a lack of consistency in the professionals seen and difficulties accessing support during working hours. As a result of such experiences, caregivers described feeling let down and alone. Caregivers also outlined the type of support and help which would have been useful for them. Both Denise and Anne expressed their wish that services were able to do more. Denise described asking for help for her son over a long period, and talked about the need for services to have more powers to be able to intervene in cases such as her son who do not present with any major risk, do not want help themselves but are clearly experiencing a decline in their mental health. Anne's son was often non-compliant with his medication, and she wanted services to have the ability to impose a treatment order so that if he continued to be non-compliant he could be returned to inpatient care.

Caregivers frequently had to cope with acute crises in the young person's behaviour and described needing out-of-hours emotional support and guidance to help them manage this. Caregivers also described the need for a respite care service due to their care role being so demanding and tiring. Many caregivers also described needing to share their experiences with other caregivers in similar situations and expressed the need for a parent support group. For other caregivers this type of support was not perceived as useful. Denise described already having the emotional support she needed from her family and that such support groups

would not have changed her situation. Steve reported having attended a parent support group but did not find the experience of talking to other caregivers as useful for him.

6.4 Recovery

Caregivers conceptualised recovery as *getting back to normal*. Experiences relating to the young person's recovery included the 'person' caregivers had known before their psychosis slowly returning, relationships being restored and normality returning within the family household. This normality meant that family members were able to get back to doing their normal everyday routines and activities. Caregivers described witnessing the young person showing signs of improvement as a positive experience. This was synonymous with them slowly being re-united with the young person they had known. Signs that the young person was recovering included having everyday conversations with their caregivers, becoming more independent a return to their prior interests and aspects of their personality returning. Caregivers described the young person's recovery as a slow process, occurring gradually over many months. Margaret, in particular, perceived her daughter's slow recovery as favourable, perhaps reflecting her need to gradually relinquish her involvement as a carer and develop confidence that her daughter was going to be okay.

Caregivers also described experiences which they perceived had been important within the young person's recovery. These experiences included the young person being within a normal everyday environment, an increase in engagement in everyday activities, medication compliance, the young person taking responsibility for their own mental health and being self-determined, the young person going back to work, the young person having the opportunity to mix socially with other people and caregivers learning to become less involved. Interestingly, many of these experiences overlap with key aspects of the recovery model, suggesting that through their experiences of providing care caregivers had developed a good grasp of the important aspects of recovery. Key elements of the recovery model include service users actively engaging with life, personal qualities such as taking control and self-motivation, the development of strategies for managing their condition and learning about their medication, having opportunities

for meaningful occupation such as employment and developing relationships with other people (Davidson, 2005).

In addition to caregivers providing a detailed description of the young person's recovery, the present study suggests that caregivers themselves go through a parallel process of recovery. As well as the young person enduring a range of distressing experiences, caregivers themselves also experienced extensive levels of distress, significant change and loss and faced a range of demanding challenges in supporting and caring for the young person. The present study suggests that such experiences are often traumatising for caregivers and that service providers should also seek to support the recovery of caregivers.

Research on the experiences of service-users in their recovery from psychosis suggests that making sense of and understanding their experiences are key processes (Thornhill, Clare & May, 2004). Likewise, for caregivers within the present study, making sense of their experiences and developing a way of understanding what had happened also appears an important process in caregivers recovering from their experiences. Caregivers also appeared to have similar support needs to those of the young person, including the need for supportive relationships, the development of coping strategies for managing their emotional distress, needing to learn about medication and different forms of treatment. As a way of addressing the needs of caregivers, Addington, Collins, McCleery and Addington (2005) describe a framework applied in Canada for supporting relatives of a person with psychosis through four key stages of recovery: managing the crisis; initial stabilisation and facilitating recovery; consolidating the gains; and prolonged recovery. During each stage of their relative's recovery the needs and ongoing difficulties of family members are assessed and interventions to address these are provided. For example, in managing the crisis during the onset of their relative's psychosis, family members are given emotional and practical support and provided with an initial explanatory model of psychosis. During this stage an assessment of family need is also carried out to identify interactions patterns which may be detrimental to their relative's recovery and their own well-being. Such an approach would seem appropriate in meeting the parallel recovery needs of caregivers described in the present study.

6.5 Hope

In line with previous studies (Tuck et al, 1997; Ganguly, Chadda & Singh, 2010; McCann, Lubman and Clark, 2009), hope was described as essential in caregiver's ability to sustain their efforts and cope with the unrelenting demands and challenges of care giving. The sub-theme title *without hope you might as well give up*, implies that in order for participants to continue caring for the young person it was essential for them to have hope that in time they could overcome their current adversity and that recovery was possible. This indicates that hope provided caregivers with the motivation to continue their efforts, particularly through times of challenge and crisis. Some caregivers perceived the need to remain positive and hopeful as being an important influence on other people such as mental health professionals continuing their efforts in supporting the young person. Denise in particular described almost having a responsibility and duty as a mother to carry hope for her son in order that other people, such as other family members and service providers, sustained their hopes and efforts to try and help him.

Caregivers described both particularised and generalised (Dufault and Martocchio, 1985) hopes for themselves and the young person. Generalised hopes expressed by caregivers were that the future would continue to bring positive experiences. In describing his generalised hopes, Steve makes the distinction between hope and ambition. This is suggestive that for Steve hope represented a general sense of the future being positive, whereas ambition related to specific goals and aspirations. Particularised hopes expressed by caregivers included that the young person would receive the treatment they required, that the young person's recovery would continue and that relapse would not occur. Caregivers often described holding more generalised hopes for the young person, such as wanting them to be well and happy. The study by Tuck et al (1997) suggested that hope often exposed caregivers to disappointment and renewed grief. Caregivers in the present study often described more generalised hopes for the young person rather than hopes for specific outcomes, and this may represent a defensive strategy against further loss and disappointment. Simply wanting the young person to be happy and well is likely to expose caregivers to less disappointment compared with specific hopes that they may return to university.

Caregivers described a range of sources which had provided them with hope. As suggested by Bland and Darlington (2002), observing improvements in the young person's health and noticing positive changes in them was described as providing caregivers with hope. Hearing stories about the positive recovery of other young people with psychosis was also described as providing caregivers with hope. Aspects of the young person's character and disposition were also described as providing hope to caregivers. Susan described gaining hope from her daughter's self-determination and strong will. Denise derived hope from her son being a positive and outgoing person prior to his psychosis and believing that these core aspects of his personality were, despite his psychosis, still intact.

In terms of sources of hope for the young person, caregivers described the importance of themselves continuing to be positive in their interactions with the young person. This suggests that caregivers had a sense of hope being built through relational processes. This relates to the theory proposed by Russinova (1999), whereby hopes are built through supportive relationships and interactions, which in turn is generative of recovery. Again illustrating the importance of relational processes, the young person was also described as gaining hope from building relationships with mental health professionals whom they liked and trusted. In addition, interactions with mental health professionals in which improvements in the young person's mental health were highlighted were also described as providing hope. Other sources of hope for the young person included them beginning to make positive plans for the future. Carol described her son as becoming more hopeful when considering his future and becoming aware that he was able to return to university. It was also suggested that the young person making comparisons with people in worse situations to their own also provided them with hope.

Caregivers also described a range of experiences which challenged and led to them losing hope. Anne described her and her family as having completely lost their sense of hope due to mental health services having repeatedly failed to provide support and help for her son, and that without services changing they would continue to be without hope. This relates to the findings of Bland and Darlington (2002) which suggests that the hopes of caregivers were influenced by the quality of support received from mental health services, such as practical support, availability at times of crisis, and involving family members in care. Anne also described her hopes as having been lost by her son not wanting to take

responsibility for himself and being unmotivated to make any changes in his life. Thinking of other people with psychosis who had endured poor outcomes was also cited as leading caregivers to feel less hopeful for the young person.

Caregivers who continued to have difficulties making sense of the young person's psychosis was also interpreted as a challenge to their sense of hope. Whilst having become more hopeful, Carol continued to have unanswered questions about her son's psychosis, suggesting a link between hope and making sense. This finding relates to the research by Perry et al (2007) and Kirkpatrick et al (2001) in which service users gained hope by being able to make sense of and finding meaning in their psychotic experiences. This suggests an overlap between processes of hope for caregivers and those of service users.

A number of models and frameworks (e.g. Nekolaichuk et al, 1999) conceptualise hope as multi-dimensional. That is, rather than people existing on a continuum between hopefulness and hopelessness, hope exists across a number of dimensions. The model proposed by Nekolaichuk et al (1999) suggests that hope is comprised of three dimensions. These dimensions are personal, situational and interpersonal. The personal dimension relates to the subjective aspects of hope such as the meaning hope has for an individual and dispositional characteristics related to their sense of hope. The situational dimension relates to elements within a situation such as predictability and risk. The interpersonal dimension relates to the interpersonal elements of hope such as caring relationships. Caregiver's descriptions of hope appear related to these three dimensions. Hope was personally meaningful for caregivers and they also perceived their own and the young person's disposition and character as related to their sense of hope. The uncertainty and risk connected to the young person's condition and the possibility of relapse suggest a situational dimension to the hopes of caregivers. Care and trust provided through their relationship with the young person and those built with mental health professionals suggest that hope was also perceived within the interpersonal dimension.

6.6 Evaluation of Methodology

In evaluating qualitative research, Elliot, Fischer and Rennie (1999) suggest the application of the following criteria: *owning one's perspective*; *situating the sample*;

grounding in examples; providing credibility checks; coherence; accomplishing general vs. specific research tasks; and resonating with readers. A number of these criteria will be used to evaluate the present study. In terms of *owning one's perspective*, Elliot et al (1999) suggest that researchers should make transparent their values, interests and assumptions which may impact on the interpretative processes and the findings of the research. This is required in order to help the reader make interpretations from the findings and for them to understand what may have influenced the findings presented. Within IPA research studies this is often referred to as the *double-hermeneutic* (Smith, Flowers & Larkin, 2009). Periodically throughout the present study I have documented my own personal reflections and attempted to outline my own subject position relating to the phenomenon being studied. My own personal and clinical experiences may have led to my focusing on certain aspects of the data. My own experiences of receiving care from my parents during my own recovery and my view that the hope purveyed by caregivers has an essential role within recovery may have created a bias in my interpretations of the data. As a psychologist in clinical training this may have led to my seeking out psychological processes within the data and to a use of psychological language with which to interpret the experiences of caregivers. Furthermore, having worked clinically within an EI service, this may have led to my focusing on data and experiences which I had previously encountered and which were familiar to me.

Situating the sample relates to the research providing a detailed description of the sample and their personal circumstances in order to allow the reader to make judgments about the kinds of people included in the research and the circumstances to which the findings apply. Within the present research, demographic information such as their gender, occupation, ethnicity and their relationship with the young person were given in addition to a detailed description of their family context and the circumstances of how they became a primary caregiver.

Providing credibility checks relates to the steps taken by the researcher to check the credibility of interpretations and the themes identified. Within the present study, master themes across all participants and a sample of the analyses for each participant were checked by the academic and field supervisor for the research. The field supervisor for the research is a consultant psychologist working within EI and had extensive clinical experience working with caregivers of young people with first episode psychosis. In addition, thoughts and reflections relating to the data were also discussed within a qualitative research support group. Additional methods of credibility checking could have included checking interpretations with participants,

using two qualitative analysts and triangulation with other data sources. Using participants as part of the process of credibility checking was considered although this was not seen as appropriate due to the possibility that this may have presented difficulties for participants in them failing to recognise and relate to the interpretations made. Resources were not available to have had two analysts, although future studies might consider this. Triangulation with other data sources such as measures of hope (e.g. State Hope Scale; Snyder et al, 2002) may have been useful as an additional credibility check.

Accomplishing general vs. specific research tasks relates to the researcher clearly defining the aims of the research and specifying the limitations in extending the findings to other contexts. The general aims of the present study were to explore the experiences of primary caregivers of a young person with FEP within the context of an EI service and to look at how hope may feature within their experiences. The findings of the present study are limited to the context of two EI services in East and West Yorkshire and are also limited to self-selecting, mainly female, caregivers of young people between the ages of 20-24 years of age. The sample excludes caregivers who are caring for a young person without support from an EI service, such as young people supported by general adult mental health services or those not receiving any support at all.

In addition, it would also seem important to consider issues relating to the use of interviews as a method of data collection. As described by Rapley (2001), the trajectory and data obtained from interviews is a product of the interactional context between interviewer and interviewee. The majority of interviews were conducted within the participant's home, and whilst efforts were taken to sensitively manage the conditions for each interview, such as requesting a quiet and private space, often other family members, including the young person themselves, were occasionally in earshot. This may have affected the accounts given by caregivers. It would also seem important to be aware of possible memory distortions and biases in the accounts given by participants. For many caregivers the events and experiences described had occurred many months and sometimes years ago. These events had often triggered significant distress, and so caution should be used in seeing their accounts, whilst meaningful, as corresponding directly with the events described.

By taking an in-depth look at the experiences of individual caregivers, the present study provided an insight into a number of areas which would seem to warrant further investigation. Areas for future research include a more detailed examination of the development and maintenance of expressed emotion within the context of FEP and beyond the critical period. Whilst a range of possible explanations have been suggested, the mechanisms behind the development of EE are still unclear. The present study suggests that EE, particularly emotional over-involvement, may develop within families due to caregivers having to regress in their relationship with the young person to a much earlier stage of parenting. The present study also suggests that critical comments towards the young person may follow caregivers making interpretations of the young person's behavior which imply that they have control over their behavior (e.g. laziness). Longitudinal research could seek to explore the development and maintenance of these aspects of EE within the context of FEP. For example, research could explore whether caregivers who report a higher need for them to parent a much younger child following the onset of their psychosis is associated with higher levels of EE (e.g. Camberwell Family Interview; Kuipers, 2006) during the period following their psychosis. The present study also suggests that caregivers have a range of parallel recovery needs, and further studies are required to develop a greater understanding of these needs and to evaluate methods of intervention to address these. Also, future studies may look at possible relationships between how caregivers and their families have made sense of a young person's psychosis and various outcomes such as impact (e.g. emotional distress), coping responses and recovery.

6.8 Clinical Implications

The findings of the present study suggest a number of implications for clinical practice. Firstly, my reflections during the interview process were that caregivers had presented with a need simply for their own personal stories and experiences of care giving to be heard and listened to. Given that caregivers often described not feeling heard or listened to by service providers this would seem an extremely valuable clinical intervention in itself. This would also support the fostering of better relationships with caregivers and provide a better understanding of their concerns and ongoing difficulties. Often clinical appointments and meetings, particularly during the onset of the young person's psychosis and during times of acute crisis,

are likely to focus on the young person's current well-being; the present study indicates that caregivers should routinely be offered a separate space to discuss their own well-being and personal difficulties relating to their care role from a very early stage. It would also be important to be aware that through providing caregivers with this space they are likely to also be making sense of what has happened.

In addition to the young person having a range of needs to facilitate their recovery, caregivers would also seem to present with a range of parallel recovery needs. These needs include the need for supportive relationships, the development of coping strategies for managing their own emotional distress, the need for information and understanding about psychosis, and space to make sense of their experiences. To support caregivers with their sense making, the information provided should be sensitively tailored to individual caregivers so that it can be incorporated within their initial attempts to make sense of what has happened and what may have caused the young person's psychosis (e.g. contextual factors and significant life events). The implications of this are that service providers should routinely assess the needs of individual caregivers in order to facilitate their parallel recovery needs. The framework previously outlined by Addington et al (2005) in which the needs of caregivers and their family are assessed during key stages of the young person's psychosis and recovery would seem to be a highly useful approach.

To facilitate the recovery of caregivers, a major need described by caregivers was their making sense of what had happened, and service providers should seek to support caregivers in this process. The emotional distress experienced by caregivers often appeared connected with their struggles with not understanding what had happened. Not understanding also led the family members and caregivers in this study to be critical and angry towards the young person. This indicates a need for EI service providers, from a very early stage of engagement, to begin to support caregivers in their sense-making. Interventions described within the present study which were described as useful for caregivers in making sense of the episode included a time line on which significant life events leading up to the episode were plotted.

Caregivers were also desperate to understand what psychosis is and what was happening to the young person; providing caregivers with information outlining

what psychosis is would seem to be a further area of clinical need. However, given that a range of explanations of what psychosis is exist (e.g. medical, systemic, stress vulnerability model), this raises an ethical dilemma for service providers in what information to provide. The present study suggests that ideally caregivers and families, rather than being told, should be supported to make sense of the young person's psychosis in their own terms. Service providers should be aware that providing caregiver's with standardised or prescribed information may inhibit their sense making.

Given the difficulties experienced by caregivers as a result of family members often having a different understanding of the young person's psychosis and holding different opinions about how the young person should be cared for, and them often blaming one another, the present study also indicates a need for service providers to support the young person's family to jointly make sense of what had happened. Elements of the Open Dialogue approach advocated by Seikkula & Olson (2003) would appear highly relevant in meeting these needs. Within the Open Dialogue approach treatment meetings are commenced immediately following the onset of young person's psychosis, and the purpose of these meetings are for the young person and their family networks to begin to develop a shared understanding and to jointly formulate treatment plans. Whilst it is unclear whether this approach could be employed within the UK due to possible cultural difference in the willingness of families and social networks to be involved and differences in the structure of mental health services, this way of working would seem suited in meeting the needs of caregivers described within the present study.

High expressed emotion within families has been found to be associated with a greater impact on family members, increased possibility of psychotic relapse and poorer long-term outcomes (Kuipers, 2006). The present study presents a possible alternative understanding for the development of EE within families, in which caregivers, due to the needs of the young person being characteristic of a much younger child, return to a much earlier parent-child relationship. This creates a relational environment whereby expressed emotion, particularly emotional over-involvement, may develop. Whilst further research is clearly needed to explore this further, this may indicate an opportunity for service providers to be attentive to the relationship between caregivers and service users so that their level of involvement is concordant with the needs of the young person. As the young person begins to

regain independence, caregivers may need support to re-adjust their relationships and to gradually relinquish their involvement.

The present study indicates that hope is important for caregivers to cope with the demands and challenges of care giving. The descriptions provided by caregivers within the present study and the extant literature suggest that hope provided by caregivers is often critical in initiating recovery (Ruscinova, 1999). This suggests a role for service providers to attend to the fostering of hope in caregivers and seek to address instances where caregivers are lacking hope. Possible interventions for fostering the hopes of caregivers suggested by the present study may include routinely highlighting improvements and positive changes in the young person in family review meetings. Providing caregivers with positive outcome stories of other young people with psychosis and facilitating discussions in which positive aspects of the young person's personality prior to them developing psychosis are identified may also be useful in fostering the hopes of caregivers. Supporting caregivers with making sense of the young person's psychosis and attending to their needs for more information about psychosis is also likely to be important in developing their hopes.

6.9 Conclusion

The present study provides a rich insight into the experiences of UK primary caregivers of a young person with FEP within the context of an early intervention service. Caregivers experienced bewildering change and upheaval following the emergence of the young person's psychosis and a loss of their previous way of life and the loved one they knew. Whilst loss emerged as a dominant theme, some caregivers described relationships as having become much closer. This may indicate that for some families relationship realignment may be part of the recovery process, suggestive that psychosis is often a reflection of difficulties within the relational context rather than of difficulties within the individual. Caregivers had an essential need to understand what was happening, and their struggles with not understanding and facing high levels of uncertainty appeared instrumental in the levels of distress they experienced. This indicates a need for service providers to sensitively support caregivers and their families in making sense of the young person's psychosis from a very early stage. The findings of the present study also

have possible implications for understanding the development of expressed emotion within families of a person with psychosis. A context for the development of emotional over-involvement may develop as caregivers are required to return to a much earlier parent-child relationship. Critical comments and hostility may develop as a result of caregivers and other family members making interpretations of changes in the young person which imply that they have control over their behavior. Further research to explore the development of these aspects of EE would seem warranted. Significant clinical implications for EI services include the need to support caregivers and their families from a very early stage to make sense and develop a shared understanding of what has happened.

Hope was described by caregivers as an essential factor in coping with the mystifying changes and loss that followed the young person's psychosis and as a motivating force towards recovery and seeking help. Caregivers were aware of the relational aspects of hope, particularly how their own sense of hope was a supportive influence in the young person's recovery. They described a range of experiences which both strengthened and weakened their levels of hope. Given the essential role of hope within recovery and coping, service providers should work closely with caregivers in order to nurture their hopes and seek to intervene in cases where levels of hope have been weakened.

REFERENCES

- American Psychiatric Association (2000). *Diagnostic and Statistical Manual IV. Washington DC; American Psychiatric Association.*
- Addington, J, Coldham, E.L. Jones, B., Ko, T. Addington, D. (2003). The first episode of psychosis: the experience of relatives. *Acta Psychiatrica Scandinavica, 108, 285-289.*
- Addington, Collins, McCleery and Addington (2005). The role of family work in early psychosis. *Schizophrenia Research, 79, 77-83.*
- Addington, J. Jones, B., Ko, T., et al (2001). Family intervention in early psychosis. *Psychiatric Rehabilitation Skills, 5, 272-286.*
- Allot, P., Loganathan, L. & Fulford, K.W.M. (2004). Discovering hope for recovery from a British Perspective: a review of a selection of recovery literature; implications for practice and systems change. *Canadian Journal of Mental Health, 21, 13-33.*
- Anderson, C., Hogarty, G. Bayer, T. & Needleman, R.A. (1984). Expressed Emotion and social networks of parents of schizophrenic patients. *British Journal of Psychiatry, 144, 247-255.*
- Anderson, J. & Adams, C. (1996). Family interventions in schizophrenia. *British Medical Journal, 313, 505-506.*
- Anthony, W.A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16, 11-23.*
- Barker, S., Lavender, T. & Morant, N (2001). Client and family narratives on schizophrenia. *Journal of Mental Health, 10, 199-212*
- Bellack, A.S (2006). Scientific and Consumer Models of Recovery in Schizophrenia: Concordance, Contrasts, and Implications. *Schizophrenia Bulletin, 32, 432-442.*
- Bentall, R.P., (2003). *Madness Explained: Psychosis and Human Nature. UK: Penguin.*
- Bertrando, P. (2006). The evolution of family interventions for schizophrenia. A tribute to Gianfranco Cecchin. *Journal of Family Therapy, 28, 4-22.*
- Bland, R. & Darlington, Y. (2002). The Nature and Sources of Hope: Perspectives of Family Caregivers of People with Serious Mental Illness. *Perspectives in Psychiatric Care, 38, 61-68.*

- Clarke, L. (2009). Hope: the eternal paradigm for psychiatric/mental health nursing. *Journal of Psychiatric and Mental Health Nursing*, 2009, 16, 843–847
- Clarke, M., Hitty, P., Browne, S., McTigue, O., Kamali, M., Gervin, M., Kinsella, A., Waddington, J.L., Larkin, C. & O'Callaghan, E (2006). Untreated illness and outcome of psychosis. *British Journal of Psychiatry*, 18, 235-24 0.
- Copeland, M.E. (1997). *Wellness Recovery Action Plan (WRAP)*. West Dummerston, VT: Peach Press.
- Cratsley, K., Regan, J., McAllister, V., Simic, M. & Aitchison, K.J. Duration of Untreated Psychosis, Referral Route, and Age of Onset in an Early Intervention in Psychosis Service and a Local CAMHS. *Child and Adolescent Mental Health*, 13, 130–133
- Czutcha, D. & Johnson, B. (1998). Reconstructing a sense of self in patients with chronic mental illness. *Perspectives in Psychiatric Care*, 34, 31-36.
- Davidson, L. (2005). Recovery, self management and the expert patient: Changing the culture of mental health from a UK perspective. *Journal of Mental Health*. 14, 25-35.
- Deegan, P. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*, 11, 11-19.
- Deegan P (1996). Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*, 19, 91-97.
- Dorsett, P. (2010). The Importance of Hope in Coping with Severe Acquired Disability. *Australian Social Work*, 63, 83-102.
- Downes, J. (2001). Starting and supporting hearing voices groups. UK: Hearing Voices Network.
- Duckworth, A.L., Steen, T.A., Seligman, M.E.P. (2005). Positive Psychology in Clinical Practice. *Annu. Rev. Clin. Psychol.* 1, 629-651.
- Dufault, K. & Martocchio, B. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America*, 20, 379-391.
- Elliot, 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.
- Ganguly, K. K. , Chadda, R. K. and Singh, T. B.(2010). Caregiver Burden and Coping in Schizophrenia and Bipolar Disorder: A Qualitative Study. *American Journal of Psychiatric Rehabilitation*, 13, 126 -142.

- Fadden, G., Bebbington, P.E. & Kuipers, L. (1987). The impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry*, 150, 285-292.
- Fortune, D.G., Smith, J.V. & Garvey, K. (2005). Perceptions of psychosis, coping, appraisals, and psychological distress in the relatives of patients with schizophrenia: An exploration using self-regulation theory. *British Journal of Clinical Psychology*, 44, 319–331.
- George, R.D. & Howell, C.C. (1996). Clients with schizophrenia and their caregiver's perceptions of frequent psychiatric rehospitalisations. *Issues in Mental Health Nursing*, 17, 573-588.
- Harding, C.M., Brooks, G.W., Ashikaga, T., Strauss, J.S., & Breier, A. (1987). The Vermont longitudinal study of persons with severe mental illness, I: Methodology, study sample, and overall status 32 years later. *American Journal of Psychiatry*, 144, 718-726.
- Herth, K.A. & Cutcliffe, J.R. (2002). The concept of hope in nursing: research/ education/ policy/practice. *British Journal of Nursing*, 11, 1404-1411.
- Houghton, J. (1982). Maintaining mental health in a turbulent world. *Schizophrenia Bulletin*, 8, 548-552.
- Huang, X.Y, Sun, F.K, Yen, W.J, Fu, C.M (2008). The coping experiences of carers who live with someone with schizophrenia. *Journal of Clinical Nursing*, 17, 817-826.
- Huber, G., Gross, G, Schuttler, R., & Linz, M. (1980). Longitudinal studies of schizophrenia patients. *Schizophrenia Bulletin*, 6, 592-605.
- Hunt, D. & Smith, J.A. (2004). The personal experience of carers of stroke survivors: an interpretative phenomenological analysis. *Disability And Rehabilitation*, 26, 1000–1011.
- Jackson, C. & Iqbal, Z (2000). Psychological Adjustment to Early Psychosis. In Birchwood, M., Fowler, D., & Jackson, C. (2000). *Early Intervention in Psychosis*. UK: Wiley.
- Janoff-Bulman, R., & Yopyk, D.J. (2004). Random outcomes and valued commitments: Existential dilemmas and the paradox of meaning. In Greenber, J., Koole, S.L., & Pszyczynski, T. (Eds). *Handbook of existential psychology* (pp. 122-138). New York: Guildford Press.

- Karanci, A.N. (1995). Caregivers of Turkish schizophrenic patients: causal attributions, burdens and attitudes to help from the health care professionals. *Social Psychiatry and Psychiatric Epidemiology*, 30, 261-268.
- Kirkpatrick, H., Landeen, J., Woodside, H., & Byrne, C. (2001). How people with schizophrenia build their hope. *Journal of Psychosocial Nursing and Mental Health Services*, 39, 46-54.
- Kruger, A. (2000). Schizophrenia: Recovery and Hope. *Psychiatric Rehabilitation Journal*, 24, 29-37.
- Kuipers, L. & Bebbington, P.E. (1985). Relatives as a source of management of functional illness. *British Journal of Psychiatry*, 147, 465-471
- Kuipers, L. (1992). Expressed Emotion research in Europe. *British Journal of Clinical Psychology*, 31, 429-443.
- Kuipers, E. (2006). Family interventions in schizophrenia: evidence for efficacy and proposed mechanisms of change. *Journal of Family Therapy*, 28, 73-80.
- Kwon, P. (2002). Hope, Defence Mechanisms, and Adjustment: Implications for False Hope and Defensive Hopelessness. *Journal of Personality*, 70, 207-231.
- Kylma, J. & Juvakka, T. (2007). Hope in parents of adolescents with cancer- Factors endangering and engendering parental hope. *European Journal of Oncology Nursing*, 11, 262-271.
- Kylma, J., Juvakka, T., Nikkonen, M., Korhonen, T., Isohanni, M. (2006). Hope and Schizophrenia: an integrative review. *Journal of Psychiatric Mental Health Nursing*, 13, 651-664.
- Landeen, J., Pawlick, J., Woodside, H., et al (2000). Hope, quality of life, and symptom severity in individuals with schizophrenia. *Psychiatric Rehabilitation Journal*, 23, 364-369.
- Langdrige D. (2007). *Phenomenological Psychology: Theory, Research and Method*. Pearson.
- Leete, E. (1988). The treatment of schizophrenia: A patient's perspective. *Hospital and Community Psychiatry*, 38, 486-491.
- Leventhal, H., Diefenbach, M., & Leventhal, E. (1992). Illness cognition: Using common-sense to understand treatment adherence and affect-cognition interactions. *Cognitive Therapy and Research*, 16, 143-163.
- Lovejoy, M. (1982). Expectations and the recovery process. *Schizophrenia Bulletin*, 8, 605-609.

- Luborsky, L., Singer, B., & Luborsky, L. (1975). Comparative studies of psychotherapies. *Archives of General Psychiatry*, 32, 995-1008.
- Lysaker P.H., Campbell K. & Johannesen J.K. (2005). Hope, awareness of illness, and coping in schizophrenia spectrum disorders. *Journal of Nervous and Mental Disease* 193, 287–292.
- Marsh, D.T. & Lefley, H.P. (2003). Family Interventions for Schizophrenia. *Journal of Family Psychotherapy*, 14, 47-68.
- McCann, T.V., Lubman, D.I & Clark, E. (2009). First-Time Caregiver's Experience of Caring for Young Adults with First Episode Psychosis. *Journal of Family Nursing*, 15, 273 – 294.
- McGorry, P.D., (2000). The Scope of Preventive Strategies in Early Psychosis: Logic, Evidence and Momentum. In Birchwood, M., Fowler, D., & Jackson, C. (2000). *Early Intervention in Psychosis. UK: Wiley.*
- McNab, C., Haslam, N. & Burnett, P. (2007). Expressed emotion, attributions, utility beliefs, and distress in parents of young people with first episode psychosis. *Psychiatry Research* 151, 97–106.
- Miller, J.F. & Powers, M. (1988). Development of an instrument to measure hope. *Nursing Research*, 2, 23-29.
- Moller, H.J. & Von Zerssen, D. (1995). Course and outcome of schizophrenia. In: Hirsh, D.R., Weinberger, D.R. Ed. *Schizophrenia. Oxford: Blackwell Science*
- Nekolaichuk ,C.L, Jevne, R.F. & Maguire, T.O. (1999). Structuring the meaning of hope in health and illness. *Social Science & Medicine* 48, 591-605.
- NICE (2002). Schizophrenia: Core interventions in the treatment and management of schizophrenia in primary and secondary care. *NICE, London.*
- Norman, R.M.G., Lewis, S.W. & Marshall, M. (2005). Duration of untreated psychosis and its relationship to clinical outcome. *British Journal of Psychiatry*, 187, 19-23.
- Nystrom, M. Svennson, H. (2004). Lived experience of being a father of an adult child with someone who has schizophrenia. *J Clin Nursing*, 17, 817-826.
- O'Toole, M.S, Ohlsen, R.I., Taylor, T.M., Walters, J. & Pilowsky, L.S. (2004). Treating first episode psychosis – the service user's perspective: a focus group evaluation. *Journal of Psychiatric and Mental Health Nursing*, 11, 319-326.
- Pakenham, K.I. (2007). Making Sense of Multiple Sclerosis. *Rehabilitation Psychology*, 52, 380-389.

- Patterson, P., Birchwood, M. & Cochrane, R. (2005). Expressed emotion as an adaptation to loss: Prospective study in first-episode psychosis. *British Journal of Psychiatry*, 187, 59-64.
- Perry, B.M., Taylor, D. & Shaw, S.K. (2007). "You've got to have a positive state of mind": An interpretive phenomenological analysis of hope and first episode psychosis. *Journal of Mental Health*, 16, 781-793.
- Poster, E. (2001). A shot at the brass ring. *Journal of Child and Adolescent Psychiatric Nursing*, 13, 5-6.
- Rapley, T.J. (2001). The art(fulness) of open-ended interviewing: some considerations on analysing interviews. *Qualitative Research*, 1, 303-323.
- Ramon, S., Healy, B. & Renouf, N. (2007). Recovery from Mental Illness as an Emergent Concept and Practice in Australia and the UK. *International Journal of Social Psychiatry*. 53, 108-122.
- Raune, D., Kuipers, E. & Bebbington, P.E. (2004). Expressed emotion at first-episode psychosis: investigating a carer appraisal model. *The British Journal of Psychiatry*, 184, 321-326
- Reed, S. I. (2008). First-episode psychosis: A literature review. *International Journal of Mental Health Nursing*, 17, 85–91
- Reid, K. Flowers, P. & Larkin, M. (2005). Exploring lived experience: An introduction to Interpretive Phenomenological Analysis. *The Psychologist*, 18, 20-23.
- Ridgeway, P.A. (2001). Re-storying psychiatric disability: Learning first person narrative accounts of recovery. *Psychiatric Rehabilitation Journal*, 24, 335-343.
- Roberts, G. & Wolfson, P. (2004). The rediscovery of recovery: open to all. *Advances in Psychiatric Treatment*, 10, 37-49.
- Robson, C. (2008). *Real World Research. 2nd Edition*. Blackwell Publishing.
- Russinova, Z. (1999). Providers Hope-Inspiring Competence as a Factor Optimizing Psychiatric Rehabilitation Outcomes. *Journal of Rehabilitation*, 24, 335-343.
- Schene, AH, Van Wijngaarden, B. Koeter, M.W.J. (1998). Family caregiving in schizophrenia: domains of distress. *Schizophrenia Bulletin*, 24, 609-618.
- Seikkula, J. & Olson, M (2003). The Open Dialogue approach to Acute Psychosis: Its Politics and Micropolitics. *Family Process*, 42, 403-418.
- Seligman, M.E.P, Rashid, T., & Parks, A.C. (2006). Positive Psychotherapy. *American Psychologist*, 774-788.

- Seligman, M.E.P., Steen, T.A., Park, N. & Peterson, C. (2005). Positive Psychology Progress: Empirical Validation of Interventions. *American Psychologist*, 60, 410-421.
- Sin, J., Moone, N. & Wellman, N. (2005). Developing services for the carers of young adults with early-onset psychosis: listening to their experiences and needs. *J Psychiatr Ment Health Nursing*, 12, 589-597.
- Smith, D.L. (2007). A Phenomenological Reflection on the Experience of Hope. *The Humanistic Psychologist*, 35, 81–104.
- Smith, J.A. (1996). Beyond the divide between cognition and discourse. Using Interpretive Phenomenological Analysis in health psychology. *Psychology & Health*, 11, 261-271.
- Smith, J.A, Flowers, P. & Larkin, M. (2009). *Interpretive Phenomenological Analysis: Theory, Method and Research*. Sage.
- Smith, J.A. (2008). *Qualitative Psychology. A Practical Guide to Research Methods*. 2nd Edition. US: Sage Publications.
- Smith, J.A. and Osborn, M (2008) Interpretive phenomenological analysis. In JA Smith (ed) *Qualitative Psychology: A Practical Guide to Methods*. London: Sage.
- Szmuckler, G (1996). From family `burden' to caregiving. *Psychiatric Bulletin*, 20, 449-451.
- Szmuckler, G.I., Burgess, P. Herman, H. et al (1996). Caring for relatives with serious mental illness: the development of experience of caregiving inventory. *Soc Psychiatr Psychiatric Epidemiol*, 31, 149-155.
- Snyder, C.R. (2000). *Handbook of Hope: Theory, Measures and Applications*. US: Academic Press.
- Snyder, C.R., Rand, K.L., King, E.A., Feldman, D.B. & Woodward, J.T. (2002). "False" Hope. *Journal of Clinical Psychology*, 58, 1003–1022
- Thornhill, H., Clare, C. & May, R. (2004). Escape, Enlightenment and Endurance: Narratives of recovery from psychosis. *Anthropology and Medicine*, 11, 181-199.
- Tuck, I., du Mont, P., Evans, G., et al (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing*, 70, 268-273.
- Unzicker, R (1989). On my own: A personal journey through madness & re-emergence. *Psychosocial Rehabilitation Journal*, 13, 71-77.

- Willig, C. (2009). *Introducing Qualitative Research in Psychology*. City University, London, UK.
- Wong, M.G. & Heriot, S.A. (2008). Parents of children with cystic fibrosis: how they hope, cope and despair. *Child: care, health and development*, 34, 344–354.
- Warner, R. (2009). Recovery from schizophrenia and the recovery model. *Current Opinion in Psychiatry*, 22, 374–380.
- Warner, R. (2004). *Recovery from schizophrenia: psychiatry and political economy*. 3rd Ed. Hove, UK: Brunner-Routledge.
- White, M. & Epston, D. (1990). *Narrative Means to Therapeutic Ends*. London: Norton & Co.
- Zubin, J. and Spring, B. (1977) Vulnerability: A New View on Schizophrenia *Journal of Abnormal Psychology* 86, 103-126

APPENDIX

Appendix 1: Service user approach letter

Dear service user

My name is Jason, I am training to be a clinical psychologist. As part of my training I am doing some research to find out more about people who support and look after someone who has had psychosis. I would like to ask for your permission to contact a person who has supported or looked after you most during and after your psychosis. These people are sometimes called caregivers. They will be asked if they are willing to be interviewed about the time they have spent helping you. This person may be a parent, partner or other family member who has supported or looked after you most during and after your psychosis.

The interview will last about 45-60 minutes. They will be asked questions about the time they spent supporting you during and following your psychosis. The aim of the research is to help improve the understanding services have about caregivers of a person with psychosis so they can improve the support they give.

It is up to you to decide whether or not to consent for your caregiver to be contacted. If you do not wish to give your consent, this will in no way affect the care you or they receive. Also, if you later change your mind, you are able to withdraw from the research at any stage.

If you decide to give permission, you will be asked to sign a consent form, on which you will also supply the contact details for your caregiver. This will then be given to me and I will keep this confidential at all times. All information provided in the interview will be kept anonymous, and when the research is written up no one will be able to tell who you or your caregiver is.

At the end of the project I will prepare a brief summary of what I have found and, if you would like a copy, this will be sent to you.

Yours sincerely

*Jason Miller
Psychologist in Clinical Training*

Appendix 2: Service user information sheet

Caregivers Experience of Psychosis

You are being asked if it would be okay to contact the person who has supported you most during and after your psychosis to ask them to take part in some research. This person does not include staff from the early intervention team, but may be a parent, partner or other family member who has helped you most during this time. These people are sometimes called *caregivers*.

Before you decide, you need to understand why the research is being done and what it involves. Please take time to read the following information carefully. Please talk to your care co-ordinator or contact the researcher using the contact information below if you want to ask any questions about the research.

PART 1 tells you about the purpose of the research and what will happen if you agree for your caregivers to be contacted. *PART 2* gives you more information about how the research will be done.

Take time to decide whether or not you wish to take part.

PART 1

➤ What is the research about?

The research involves talking to caregivers about their experiences of caring for a person during and after psychosis. The aim is that this information will help gain a better understanding of the experiences of caregivers who look after someone with psychosis and be used to help services understand how they may improve the support they give caregivers. The research is being carried out as part of the researcher's training at Leeds University to be a clinical psychologist.

➤ Why have I been asked?

You have been asked as you are currently receiving a service from an early intervention in psychosis team. Your care co-ordinator thought you might be willing for your caregiver to take part. You are amongst a number of young people who have been approached and it is hoped that up to ten caregivers will take part in the study.

➤ Do I have to take part?

It is up to you to decide. If you agree for your caregivers to be contacted, please tell your care co-ordinator. They will ask for you to sign a form which says it is okay for them to be contacted. You are free to change your mind at any time, without giving a reason and this will have no affect on you or your caregivers.

➤ What will happen to me if I take part?

If you agree to take part, your caregivers will be contacted to ask if they would like to be interviewed. This interview will last about an hour. Interviews will take place either at an office of the early intervention service or at your caregiver's home, depending on their preference. They will be asked questions about their

experiences of supporting you during and following your first episode psychosis. The interview will be tape-recorded. The tapes will be kept safe and locked away at all times. All information will be kept confidential, which means no one else other than myself and the people who are helping me with the research will have access to it. Any information which I include in the report of the research will be anonymous, meaning no one will be able to tell who you or your caregivers are.

➤ What are the possible benefits of taking part?

Your caregivers may find talking about their experiences beneficial. It is also hoped that findings from the study will help services which work with young people and their carers.

➤ What are the possible disadvantages of taking part?

It is possible that during the interview personal and upsetting events may be discussed. Should your caregiver become upset or need to talk to someone after the interview the researcher will help them with this.

If you may be interested, Part 2 tells you more about the research.

PART 2

➤ What will happen if I don't want to carry on with the research?

Only if you sign the consent form will your caregivers be contacted. You are free at a later time to change your mind and any information collected from your caregivers will be destroyed.

If you have any concerns about any aspect of the research, you should speak to your care co-ordinator or to the researcher who will do their best to answer your questions. If you are still unhappy you can complain by contacting the address at the end of this information sheet.

➤ Will my taking part in this research be kept confidential?

No one other than the researcher and staff from the early intervention service will have access to yours' and your caregivers personal information (e.g. name, address and telephone numbers).

Information collected in the interview will be recorded, although no one other than the researcher will be able to tell who you or the person being interviewed is. The recorded interview will then be typed up. This information will be kept on a computer system which can only be accessed by myself. Information from the interview will be used in the findings and research report, although this will be done anonymously which means that no one will be able to tell who you or your caregivers are.

The information gathered will only be used for this piece of research and will not be used by others. The information collected will be kept for seven years at Leeds University and will then be destroyed.

As part of my role, I am required to break confidentiality should I have any concerns about any potential harm to children or harm to you or others.

➤ What will happen to the results of the research?

The results of the research will be used as part of the researcher's training to be a clinical psychologist and will be published. You can get a summary copy of the findings and research report if you wish. You and your caregivers will not be identified in the findings or research report.

➤ Who is organising and funding the research?

The University of Leeds is paying for the research. I am not being paid for doing it, it is part of my training to conduct this research.

➤ Who has reviewed the research?

All research in the NHS and similar health services is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights and wellbeing.

➤ Further information and contact details

If you decide to participate you will be provided with a copy of this information sheet.

If you wish to get more information about the study at any point please contact the researcher:

Jason Miller
Psychologist in Clinical Training
Leeds Institute of Health Sciences
Charles Thackrah Building
101 Clarendon Road
Woodhouse
Leeds. LS2 9JL
Tel: 07981928788

If you are unhappy with this study you should approach;
Humber Mental Health Teaching NHS Trust
Trust Headquarters
Willerby Hill
Tel. 01482 223 191

Thank you for your time!

Jason Miller
Psychologist in Clinical Training

Appendix 3: Caregiver approach letter

Dear *caregiver*

The purpose of this letter is to invite you to take part in some research. The research is part of my training as a clinical psychologist at Leeds University. *Service user's name* has given their permission for you to be contacted and has informed me that you were one of the main people who have supported them during and after their psychosis. People such as yourselves are often referred to as *caregivers*.

I would be very grateful if you would be willing to take part. The research will involve an interview with myself and will involve questions about your experience helping *name* during and following their psychosis. The interview will take around 45-60 minutes and be held at a time and place suitable for you. It is hoped that the findings from the research will be used to inform psychosis services about the experiences and needs of caregivers and so help improve the support they give.

It is up to you to decide whether or not to be interviewed. More information about the research is given in the enclosed information sheet. If you do not wish to take part, this will in no way affect the care you or anyone else receives. You are also free to withdraw from the research at any stage.

If you are willing to take part or have any questions about the research, please contact me on telephone number. If I do not hear from you within 10 working days, I will send you a reminder letter asking you to get in touch if you would like to take part. If you decide to be interviewed, you will be asked to sign a consent form prior to the interview.

Yours sincerely

Jason Miller
Psychologist in Clinical Training

Appendix 4: Caregivers information sheet

Caregivers Experience of Psychosis

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you.

If you would like someone to go through the information sheet with you and answer any questions you may have, please contact the researcher on the number below

PART 1 tells you about the purpose of the research and what will happen to you if you take part and *PART 2* gives you more detailed information about the study.

Take time to decide whether or not you wish to take part.

PART 1

- What is the purpose of the research?
The purpose of this research is to explore the experiences of primary caregivers (including parents, relatives, friends and partners) who have cared for a person with psychosis. The research will involve talking about your experiences in an interview which will last between 45-60 minutes.
- Why have I been invited?
You have been identified as being a caregiver of a person who has experienced an episode of psychosis, and this person has given their permission for you to be contacted. You are amongst a number of caregivers who have been approached and it is hoped that a total of about ten caregivers will take part.
- Do I have to take part?
It is up to you to decide. You are free to withdraw at any time, without giving a reason and this will in no way affect the care any of you receive.
- What will happen to me if I take part?
If you agree to take part it will involve an interview, which will last approximately 45-60 minutes. If you would like to take part please contact the researcher on the telephone number below. If we do not hear from you within 10 days, a reminder letter will be sent, reminding you of the research and to contact the researcher if you would like to take part.

If you decide to take part, you will be asked to sign a consent form to show you have agreed to take part. Interviews will take place either at the offices of the early intervention service or at your home, depending on your preference, and will be arranged for a time convenient for you.

During the interview, you will be asked questions about your experiences of caring for a person during and following their psychosis. The interview will be tape-recorded. The tapes will be kept locked away and destroyed on completion of the study. Quotes from the interview will be used in the research report and may be

published, however all identifiable information will be removed so no one will be able to tell who you are.

- Will I be paid to take part?
You will only be paid for your travel expenses. If you incur any travel expenses whilst taking part in the research, these will be paid back to you..
- What are the possible benefits of taking part?
Many caregivers find it useful to talk about their experiences. It is also hoped that the findings from the research will improve the understanding services have of people who look after someone with psychosis, and so improve the support they give.
- What are the possible disadvantages and risks of taking part?
It is possible that during the course of the interview you may become upset as part of explaining your experiences. Should this occur, please feel free to discuss this with the researcher. If you feel you would like further support following the interview, with your consent, a member of the early intervention service will be asked to contact you.
- Will my taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If you are considering taking part, please read the additional information in Part 2 before making any decision.

PART 2

- What will happen if I don't want to carry on with the interview?
You will be free to terminate the interview at any point and ask for your information to be withdrawn should you wish.
- Complaints
If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Relations Manager whose contact details are given below.
- Will my taking part in this study be kept confidential?
Confidentiality will be safeguarded during and after the study. Our procedures for handling, processing, storage and destruction of their data match the Caldicott principles and the Data Protection Act 1998.

The information you give in the interview will be tape-recorded. The recordings will then be transcribed onto a computer package. This will be stored securely on a password-protected computer. Paper information will be stored securely at the University of Leeds.

The information gathered will be used only for the purposes of the present study and will not be available for future researchers to access. Only the researchers will

have access to identifiable data. The data collected will be retained for seven years at Leeds University and will then be destroyed. All information which is collected about you during the course of the research will be kept strictly confidential.

The researcher is professionally bound to break confidentiality should any concerns be raised regarding child protection or harm to self or others.

- What will happen to the results of the research?
The results of the study will be used as part of a doctoral thesis and will be published. These documents will be made available to you should you wish. A summary of the findings will also be made available to you on completion of the research. You will not be identified in any report or publication.
- Who is organising and funding the research?
The University of Leeds is organising and funding the research. The researcher is not being paid for this piece of research, though it is a requirement of the researcher's training as a clinical psychologist to undertake such a research study.
- Who has reviewed the study?
All research in the NHS and healthcare services is looked at by an independent group of people, the Research Ethics Committee, to protect your safety, rights, wellbeing and dignity.

Further information and contact details

If you wish to receive further information about the study at any point please contact the researcher:

If you wish to receive further information about the study at any point please contact the researcher:

If you are unhappy with this study you should approach:

Jason Miller
Psychologist in Clinical Training
Leeds Institute of Health Sciences
Charles Thackrah Building
101 Clarendon Road
Woodhouse
Leeds. LS2 9JL
Tel: 07981928788

Humber Mental Health Teaching NHS
Trust
Willerby Hill
Willerby
Tel. 01482 223191

Thank you for your time!

Jason Miller
Psychologist in Clinical Training

Appendix 5: Interview schedule

The purpose of this interview is to find out about your experience supporting and caring for name. I'm going to ask a series of questions about four main periods and how these were for you: leading up to their psychosis, during their psychosis, during their recovery so far and the potential future. Please feel free to ask any questions throughout the interview and please take your time to think about your responses.

- Please could you tell me about the time when you first noticed changes in *name*?
Prompts: *What changes did you notice? What did you think was happening? How did you feel during this time? What impact did this have for you? How did you find out that the changes you had noticed were psychosis?*
- During *name*'s psychosis, how was this time for you?
Prompts: *What did their psychosis involve for you? What changed for you during this time? What was most difficult? How did you support/help/care for name? What sorts of things helped/hindered you? How did it affect your relationship with them? How do you think this time was for other people (e.g. name, family members, other people in household, partners etc.)?*
- During the time of their psychosis, I was wondering if *hope* might have meant anything for you?
Prompts: *In what ways was hope important to you during this time? What did hope give you? How would you define what hope meant for you during this time? Where did your hope come from during this time? What influenced your levels of hope during this time? What things increased/decreased your hope? During this time, how do you think hope was important for name?*
- During *name*'s recovery, how has this time been for you?
Prompts: *What has their recovery involved for you? How did you support/help/care for name during their recovery? What has changed during their recovery? What has been most difficult during this time? How has this time affected your relationship with them? What has helped/hindered you during their recovery? What has recovery meant for you? What has been important for you during their recovery? How has the recovery been for others (e.g. name, family members, other people in household, partners etc.)?*
- During *name*'s recovery, I was wondering if *hope* might have meant anything for you?

Prompts: *In what ways was hope important to you during this time? What did hope give you? How would you define what hope has meant for you during this time? Where did your hope come from during this time? What influenced your levels of hope during this time? What things increased/decreased your hope? During their recovery, how do you think hope was important for name?*

- How do you see the future?
Prompts: *What might the future involve for you? What might the future mean for you? What support/help/care do you think you may need to provide for name? What do you think may change? What might be most difficult for you? How do you see your relationship with name in the future? What might help/hinder you? What might be important for you in the future? How might the future be for others (e.g. name, family members, other people in household, partners etc.)?*
- Could you tell me about anything else you believe is important that we haven't already discussed?

Appendix 6: Super-ordinate themes

Table 3

Themes for Interview 1

Theme Name	Description	Extract
It happened so fast		
	Very quick onset	<i>It happened very quickly</i> <i>p. 1 7</i>
	Shock and confusion	<i>It happened so fast, it shocked me. I didn't even know what a psychotic episode was</i> <i>P.3 59</i>
	Sensing something not right	<i>[daughter] is not too well</i> <i>P. 1 15</i> <i>I said she certainly isn't right</i> <i>P.1 21</i> <i>I thought oh dear, this can't be right at all</i> <i>P. 2 29</i> <i>The lady [at daughter's work] who answered said I'm not surprised, she didn't seem right yesterday, she didn't seem right.</i> <i>P.1 21</i>
	Very disturbed by her thoughts	<i>She came home on Thursday saying her dad was going to be sacked and so was her sister. She was worried about the BNP. Very worried about</i>

		<i>her boyfriend.</i>
		<i>p. 1 8</i>
		<i>she was very afraid</i>
		<i>p. 6 134</i>
Seeking help from within existing support network		<i>Meanwhile I went to the neighbour, whose father is our doctor. I said to P ring your dad, and tell him [daughter] isn't right. P. 2 32</i>
I didn't know what I was protecting her from or how to look after her		
Psychological impact	Needing to understand and not understanding being very frightening	<i>Understanding it, understanding what had happened to [daughter]. Why it had happened.</i> <i>p. 4 76</i> <i>So, it's just so frightening at the time not understanding it</i> <i>p. 5 114</i>
	Anxiety provoking and worrying	<i>If it was ever to happen again I wouldn't be so anxious or worried as I was the first time</i> <i>p. 16 342</i>
	Fearing that FEP may be life-long	<i>At first I thought [daughter] was never ever going to come out of this, she was going to be like that for the rest of her life</i> <i>p. 15 323-324</i>
	Guilt	<i>How had I missed it?</i> <i>p. 4 77</i>
	Loss/living with different person	<i>There's still a piece of E that is missing</i>

Challenges	Balancing involvement vs over-involvement	<i>She has to look after her sister, watch her, just keep an eye on her, keep in touch, not to interfere but to be there if needed her</i> <i>p. 15 317-320</i>
	Challenge of managing/supporting with fears and thoughts	<i>p. 1 7-23</i>
	Shattering and tiring	<i>I think it's worn me out. It shattered me</i> <i>p. 6 116</i>
	Like caring for younger child	<i>We had to try and stop her from getting upstairs to me</i> <i>p. 5 98</i>
	Needing to be patient but finding this most difficult	<i>My patience. Because I don't have much patience</i> <i>p. 8 175</i>
	Wanting to protect and help but not understanding	<i>I didn't know what a psychotic episode was. I couldn't protect [daughter] because I didn't know what I was protecting her from</i> <i>P. 3 59</i>
	Needing to have a rest	<i>Perhaps you might have to go if it's going to let dad and I have a rest from you</i> <i>P. 12 262</i>
Impact and difficulties for others	Importance of both parents being involved	<i>[father] came back if the doctor was coming, erm, my husband would come back for that. He came home as much as he could</i>

	<p><i>P. 14 297</i></p> <p><i>we had about four or five nights where [daughter] was awake all night and my husband and I took shifts looking after her</i></p> <p><i>p. 5 95</i></p> <p><i>My granddaughter has had to go through this as well, and she idolises her auntie. You could see her physically step back from auntie because she wasn't quite with her on what she was talking about. Her mum explained to her that her auntie wasn't quite well</i></p> <p><i>P. 10 214</i></p> <p><i>It was a very hard thing for a little child to understand</i></p> <p><i>P. 10 221</i></p> <p><i>The eastern block seem to have a fear of mental health, they seem to shut it away...I think that's the fear that boyfriend had, that's why he finished with her.</i></p> <p><i>P. 13 286</i></p> <p><i>He was trying to go to work. So in the end, work said take a few days off whilst she's at this stage which my husband did. Which was good, because then we were both at home and could help</i></p> <p><i>P. 5 100</i></p>
Younger family members not understanding/loss	
Boy friend not understanding – cultural differences	
Needing to be flexible with work arrangements and work understanding	

Getting back into the swing of things

***Getting back to
normality***

Resuming routine

My husband was glad to get back to work, back to normality. It's being normal again

p. 14 294

We stayed in, we took [daughter] out for walks, I still went up to my daughters, to my daughter's house everyday. We walked the dog.

Supporting with normal activities

I would take the dog out and she would sit upstairs until I had finished what I was doing. Then we would go home again. She did get better. Now she's fine with the dog

p. 7 138

***You're taking that tablet
if it's the last thing you
do***

It's so important that tablet

It's just so important that tablet.

P. 8

'they put my mind straight'

P. 8 180

Medication as a way of life

If she can't come off the tablets, it's not so terrible, when you think of someone with diabetes who has to inject them self every day, I said what can be the problem with taking tablets every day?

p. 7 148

Difficulty with taking tablets

[daughter] is not a lover of tablets, its taking them that she finds difficult p. 9 184

	Medication being subject of disagreements	[daughter] would say I'm not going to take the tablet. I said you're going to take the tablet if it's the last thing you do. You're going to take the tablet P. 8 176
<i>I'm still watching</i>	Constantly watching and looking for changes	<i>I'm still watching. I find I'm still watching just to make sure she's alright. Erm, if I see any slight change, I was saying to her are you feeling alright, are you sure you're ok?.....But I'm watching all the time p. 6 116-120</i>
<i>It was lovely seeing her improving</i>	Being able to manage and do normal things	<i>It was lovely to be able to go out with her.....well she can go anywhere she wants now p. 8 166-172</i>
	Seeing signs of personality coming back	<i>When you see photographs of [daughter] before it happened, there's a very vivacious girl there that's full of life and that is slowly coming back. p. 7 153</i>
	Difficult, slow and gradual, better that way	<i>And it was slow, but that's good. I think it's far better if it's slow P. 8 172</i>
	Seeing signs of improvement	<i>It was lovely to see her improving P. 8 172 I think seeing [daughter] coming out of it was a good thing, really really good at coming back to chatting and</i>

		<p><i>talking, slowly coming away from everything that she felt was wrong</i></p> <p><i>p. 11 245</i></p> <p><i>It was nice having [daughter] come back to normal, talking to me normally</i></p> <p><i>p. 12 256</i></p>
	Lifting of pressure on mother	<p><i>It took a lot of pressure off, not so much pressure</i></p> <p><i>p. 8 164</i></p>
<i>We can laugh about it now</i>	Use of humour important as way of coping	<p><i>p. 2 33</i></p> <p><i>p. 17 369</i></p> <p><i>p. 12 256</i></p>
Hopefully its opened her mouth to me		
	Need for mother-daughter relationship changes/becoming closer	<p><i>That is one thing that has improved now, that [daughter] does talk more now. Which is lovely.</i></p> <p><i>p. 9 198</i></p> <p><i>Thats want I want to know and for her to just chat like you would normally do. Like mothers and daughters do. So thats what I expect from [daughter]</i></p> <p><i>p. 10 203</i></p> <p><i>hopefully its opened her mouth to me and will say mum I'm not right, I don't feel right. P. 17 363</i></p>

That's what I call being well looked after

Quick and regular contact	Services got involved quickly – gave assurance	<i>But they came back saying the crisis team were coming. The next day, which was Sunday. Which was great. ...then someone was coming there everyday. Coming everyday</i> <i>p. 2 37</i>
Person-centred	Importance of treatment plans being based around needs of individual and having choice	<i>[daughter] was happier to be where she was doing what she was doing...so Dr B said no, I'm not having [daughter] go where she doesn't want to go, if [daughter] wants to stay at home and be here and go out for walks with you that's far better</i> <i>p. 12 264</i>
	Importance of both parents being involved in treatment plans and meetings	<i>p. 2 44-56</i>
Someone we knew and liked	Importance of professionals being caring and understanding	<i>She enjoyed his visits when he came, because he asked her questions that she felt were right for her and she could give the answers to Dr B</i> <i>p. 3 66</i>
	Regular and consistent contact with	<i>The other person was the support worker, C, who came, C was very understanding of [daughter], she liked C and we preferred her to come than Dr B.</i> <i>P. 4 70</i> <i>Then someone was there every</i>

	professionals – building relationships	<p><i>day. Coming every day</i></p> <p><i>p. 2 40</i></p> <p><i>Seeing someone on a regular basis, someone we knew and liked</i></p> <p><i>p. 3 64</i></p> <p><i>he came about half a dozen times just to see....One of the people was Dr B.. [Daughter] made a relationship with Dr B.</i></p> <p><i>p. 3 65</i></p>
<i>We've had people to our home</i>	Care meeting and appointments being delivered at home very important, although invasive at times	<p><i>We've had people to our home, I know we found that sometimes we were being invaded by people but at the same time they were here to help [daughter] and did so.</i></p> <p><i>P. 11 242</i></p>
	Not admitted to hospital seen as positive	<p><i>Because I thought I was going to have to visit [daughter] in hospitalThat what I thought and that didn't happen. She's had doctors to the house....</i></p>
	Support groups offered, whilst not attended seen as positive	<p><i>There was support groups that we could go to...and if we felt the need of that we would have done it...</i></p> <p><i>p. 12 267</i></p>
	Important that professionals are available/contactable if deterioration occurs	<p><i>So if {daughter} were to go wrong again then we would up the dose straight away and ring SW, and he would come and see her</i></p> <p><i>P. 16 349</i></p>

<i>What it meant?</i>	Timeline important intervention in making sense of psychosis – series of stressful life events	<i>When you go through the life line that they do, they went back to July and the other day I was just thinking....so [daughter] was under quite a lot of stress, from a lot of places. Erm, when you hear all the stress, it builds up</i> p. 4 77-91
	Needing professionals to explain psychosis (use of metaphors)	<i>Eventually I asked C what it was, what it meant...she said if you look at it like that, it's a jumble of the mind...</i> p. 15 327
	Hearing other people's stories of recovery useful	<i>And when you see that people come out of these episodes and that they can live a normal life</i> p. 15 331
<i>There's a lot more needs to be done with children in schools</i>	Need for education in schools about mental health so people are more understanding	<i>I think there's a lot more needs to be done with children in schools.....so I think children who are a bit older should take this on board, people should be talking to them about mental health. Not to be afraid of it</i> p. 10 209-224
<i>You couldn't have asked for better</i>	Very good care received	<i>[daughter] has been well looked after, you couldn't have asked for better. That's what I call being well looked after</i> p. 11 235

NHS seen as very good and valued	<p>When I heard the Americans say the NHS is this and that, I thought you're out of your tree, you really don't know. You know, what's going on, we have a very good NHS</p> <p>P. 11 237</p>
Hopes – to be right and well	
<p><i>As long as she is alright, that's all I ask</i></p>	<p>Adjusting future hopes , to be well and happy, enjoying life</p> <p>For me, as long as [daughter] is alright, that's all I ask. It's not a lot out of life, but it has to be enjoyed.</p> <p>P. 16 354</p> <p>I just want [daughter] to be alright and happy....just to be happy, to be happy...</p> <p>p. 17 363</p> <p>The only hope I want for [daughter] was for [daughter] to be right and well</p> <p>p. 7 147</p>
<p><i>They can live a normal life</i></p>	<p>Having a speedy response from services</p> <p>Resuming normal life and activities, doing more, 'getting into stride'</p> <p>These people came so quickly, it worked so well</p> <p>p. 15 325</p> <p>at least she's doing something...she's getting back into the swing of thing, getting back into her stride, she's been out with her friends</p> <p>p.15 335</p> <p>I'm happy with the way things are and I would like that to continue</p> <p>p. 16 340</p>

<p>Needing to understand (use of metaphor) psychosis</p>	<p>The mind is just not thinking straight, it's jumbled, that was a great help. p. 15 330</p>
<p>Daughter being compliant with medication</p>	<p>It's just so important that tablet p. 8 177</p>
<p>Hearing positive recovery stories about others, and making comparisons with people in worse situations</p>	<p>When you see that people can come out of these episodes and that they can live a normal life, and alright it may take a while P. 15 333</p>
<p>Not being admitted to hospital</p>	<p>The ones we met had had terrible, terrible times trying to see a psychiatrist, a psychologist, anybody...they were put onto mental wards...[daughter] had none of that... p. 11 228</p> <p>Because i thought I was going to have to go down to a hospital...that's what I thought...and that didn't happen p. 11 233</p>
<p>Needing plans for possible deterioration e.g. medication, who to contact</p>	<p>It if was to happen again, which I hope it doesn't, but if it ever was to happen again I wouldn't be so anxious or worries as I was thr first time, because i know who to phone....he would come and see [daughter] and up the</p>

		tablets. p. 16 344
	Needing to know mother-daughter communication better, so will tell if deteriorates	Hopefully its opened her mouth to me and will say mum... p.16 362
	Adjusting to recovery being a slow and gradual process	And it was slow, but that good. I think its far better if its slow P. 8 172
	Not being afraid of mental health problems	Not to be afraid of it p. 10 224
<i>I worry about the future</i>	Worry and anxiety about future	I worry about the future...when I die you have to look after her p. 14 315
	Thinking daughter may always have psychosis	I thought [daughter] was going to be like that for the rest of her life P. 15 324

Appendix 7: Master themes

Table 4

Master Themes

Theme	Line number of theme within each interview					
	Margaret	Carol	Susan	Denise	Anne	Steve
An Episode of change and loss						
<i>The emergence of change</i>	29	436	39	1224	101	61
<i>Such a different person</i>	152	481	288	253	117	251
<i>It affected just about everything in the house</i>	95	487	288	253	117	251
<i>We were like a prisoner</i>	116	499	1259	--	590	263
A struggle to understand						
<i>I wish I could understand</i>	221	21	23	1377	1819	447
<i>It's so frightening at the time not understanding it</i>	--	372	1130	365	442	--
<i>Not knowing what's going to happen</i>	59	596	1146	426	532	--
<i>Everybody has a different opinion</i>	323	868	393	1177	1927	175
<i>Nobody would</i>	--	441	--	401	766	529

<i>listen</i>						
Getting Help						
<i>The hardest thing we've ever had to do</i>	--	327	--	398	188	--
<i>That's what I call being well looked after</i>	37	535	1058	--	--	--
<i>The services let you down</i>	--	267	--	351	278	--
<i>We could have done with</i>	267	779	1130	1277	1083	721
Getting Back to Normal						
<i>Slowly coming back</i>	245	615	1371	302	548	698
<i>The ingredients of recovery</i>	335	848	1318	289	548	698
Hope Kept Us Going						
<i>Without hope you might as well give up</i>	147	--	984	698	1467	413
<i>That's where my hopes come from</i>	362	531	762	583	--	391
<i>That's why I lost it</i>	315	772	--	1079	583	--
<i>Not hoping for anything extra special</i>	354	465	--	1008	--	--

Appendix 8: Reflections

Reflections Prior to Beginning Study

Why am I carrying out this study?

The origins of my interest in hope and its role in recovery are my own personal experiences of recovering from depression during my mid-twenties. Often during this time I lost my sense of hope that my future would be okay. I was very fortunate that my external environment provided me with hope. Friends and, most importantly, my parents purveyed and held a sense of hope that I would okay, and I have since reflected on this as critical within my getting better. My interest in the role of hope within FEP emerged through my many encounters with young people who had and were experiencing psychosis. Their distress was often overwhelming, frequently causing a state of complete hopelessness. Through working with families and the young person's social network, it appeared critical to engage these important people. This led me to consider the role of hope for parents and caregivers in assisting them through the trauma of having a child experience psychosis, and also how they purvey hope to their children. Parents, as did mine, spend significantly greater time with their children than any clinician or service, except possibly where an admission to an inpatient service is required or feasible. If hope is critical to recovery, assisting parents to regain their own hope and convey this in an optimal way to their child would seem a fundamental intervention conducted by mental health services and other agencies which become involved during and following FEP.

What do I hope to achieve with this research?

I hope to achieve an understanding/insight into whether and in what ways hope is important for primary caregivers. I am particularly interested in how hope may feature within their own coping and their perceptions of how hope may influence the support/care they provide to a young person with FEP and whether they perceive hope to be important for the young person.

What is my relationship to the topic being investigated?

I consider myself to have an insider relationship with the topic being studied; firstly, for having recovered from psychological distress myself and found hope an

important feature of my recovery; secondly, I have also worked with family members and caregivers of a person with FEP and observed the purveying of hope within my relationships with them and their relationship with the young person very important.

Who am I, and how might I influence the research I am conducting in terms of age, sex, class, ethnicity, sexuality, disability and any other relevant cultural, political or social factors?

My own family background, which has been my major support network throughout my life, comprising of both my biological parents who have always been together throughout my life, has shaped my view of the family and how this functions. This is likely to have an influence in my interpreting the experiences of caregivers when describing family relationships etc.

How do I feel about the research work?

I am very passionate about the need to understand the difficulties and experiences of primary caregivers. Influenced by my own experiences and clinical work/training, I see it as critical to be aware of the systemic context within clinical work, seeking to include family members and important others throughout. I view *hope* to very important within psychological wellbeing and that being hopeful during times of psychological trauma and distress is critical in recovery. When a person becomes overwhelmed by their distress, and so by may lose their own sense of hope, the people close to them become critical in providing a sense of hope that things will improve, which becomes a very important motivational source.

How will my subject position influence the analysis?

Seeing hope as critical is likely to influence me in seeking this out within the analysis. My own recovery and experiences within my family during this time is also likely to impact on how I interpret the data.

How might the outside world influence the presentation of findings?

My reading of the research literature is likely to influence how and what I present. My supervisor's view of what is important to present is also likely to impact on the findings. Doing the research as part of my clinical training and needing to satisfy the requirements of this training is also likely to impact on the presentation of my findings.

How might the findings impact on the participants?

I am aware that participants talking about their experiences may be difficult and emotional for them. Whilst they are consenting to talking about their experiences, I need to be aware of their wellbeing during carrying out the research and facilitate any ongoing support that they may require. I would hope that the findings from the research can be used to improve the support given by EI services to caregivers.

How might the findings impact on the discipline and my career in it?

I would like to think that the findings will be useful for EI services in understanding the needs of caregivers and to think about how they can support families and caregivers with the difficulties and challenges they face in looking after a young person with FEP. Seeing hope as being important in recovery, I would like to identify ways in which services can better support caregivers, to also identify ways in which services can support caregivers in remaining hopeful during FEP, to understand ways in which hope can be purveyed by caregivers to young people experiencing FEP. Seeing hope and the relational contexts as critical, I expect this research to have a lasting impact on my career in terms of the way I practice and approach clinical work.

How might the findings impact on the wider understandings of the topic?

I would like to influence the way colleagues approach their clinical work by encouraging them to see the giving and restoring of hope as a very important ingredient in recovery from psychological distress. Mainstream views of psychosis and families within which psychological distress is present tend to be very bleak and negative, lacking in hope for people who experience major forms of psychological distress. It would seem important that views held within wider society purvey hope for those experiencing psychological distress and my research might contribute in some way to this.

Reflections Prior to Analysis

Why am I carrying out this study?

As previously outlined, one major source of my interest in the experiences of caregivers and the role of hope within the context of psychological distress are my own personal experiences of recovery. My interest in the experiences of primary caregivers and the role of hope within the context of FEP emerged through my many encounters with young people who had and were experiencing psychosis as an assistant psychologist in an EI team. Theirs and their family's distress was often

overwhelming, often leading to a state of hopelessness. Through working with families and the young person's social network, it appeared critical to work with and support these important people. Parents and families were observed as key players in the recovery process. This led me to consider the experiences of primary caregivers and what kept them going through the difficult task of looking after and supporting a young person with psychosis. Was hope important?

What do I hope to achieve with this research?

I would like to gain a detailed understanding of the experiences of primary caregivers in looking after and supporting a young person with first episode psychosis. Within the experiences of primary caregivers, I would like to gain an understanding of what hope means to them, what gives them hope and what lessens their levels of hope. Also, what are their perceptions of how their own hope impacts on the recovery of the young person? And do they perceive hope to be important for the young person themselves?

What is my relationship to the topic being investigated?

I consider myself to have an insider relationship with the topic being studied; firstly, for having experienced my own family to have been critical in my recovery; secondly, within my recovery, I have found hope purveyed by caregivers to be very important; thirdly, I have also worked with family members and caregivers of a person with FEP and observed the purveying of hope within my relationships with them and their relationship with the young person very important.

Who am I, and how might I influence the research I am conducting in terms of age, sex, class, ethnicity, sexuality, disability and any other relevant cultural, political or social factors?

My own family background, which has been my major support network throughout my life, comprising of both my biological parents who have always been together throughout my life, has shaped my view of the *family*. This is likely to influence my interpretation of caregiver's experiences relating to family relationships etc. Not having children myself may limit my being able to fully empathise with the experiences of parents.

How do I feel about the research work?

I am very passionate about the need to understand the difficulties and experiences of primary caregivers. Influenced by my own experiences and clinical work/training, I see it as critical to always adopt a systemic approach within clinical work, seeking

to include and support family members and important others. I view *hope* as very important within psychological wellbeing and that being hopeful during times of psychological trauma and distress is critical in recovery. When a person becomes overwhelmed by their distress, and so by may lose their own sense of hope, the people close to them become critical in providing a sense of hope that things will improve.

How will my subject position influence the analysis?

Seeing hope as critical is likely to influence me in seeking this out within the analysis. My own recovery and experiences within my family during this time is also likely to impact on how I interpret the data.

How might the outside world influence the presentation of findings?

My reading of the research literature is likely to influence how and what I present. My supervisor's view of what is important to present is also likely to impact on the findings. Doing the research as part of my clinical training and needing to satisfy the requirements of this training is also likely to impact on the presentation of my findings.

How might the findings impact on the participants?

I am aware that participants talking about their experiences may be difficult and emotional for them. Whilst they are consenting to talking about their experiences, I need to be aware of their wellbeing during carrying out the research and facilitate any ongoing support that they may require. I would hope that by talking about their experiences, whilst for the purposes of my research, may be a useful process for them in making sense of what has happened and having the opportunity and space within which they can freely tell their story.

How might the findings impact on the discipline and my career in it?

I would like to think that the findings will be useful for EI services in understanding the needs of caregivers and to think about how they can support families and caregivers with the difficulties and challenges they face in looking after a young person with FEP. Seeing hope as being important in recovery, I would like to identify ways in which services can better support caregivers, to also identify ways in which services can support caregivers in remaining hopeful during FEP, to understand ways in which hope can be purveyed by caregivers to young people experiencing FEP. Seeing hope and the relational contexts as critical, I expect this

research to have a lasting impact on my career in terms of the way I practice and approach clinical work.

How might the findings impact on the wider understandings of the topic?

I would like to influence the way colleagues approach their clinical work by encouraging them to see the giving and restoring of hope as a very important ingredient in recovery from psychological distress.

Reflections Following Analysis

Why am I carrying out this study?

My personal reflections on the importance of the hope provided by my parents during my own recovery were an initial influence on my carrying out this study. In addition to these personal experiences, my experiences of working with parents and caregivers during my clinical work both as an assistant psychologist and as psychologist in clinical training developed my awareness of the critical role played by caregivers in recovery. Since looking at the literature on hope and the recovery model, this has further affirmed my belief in the critical role of hope for people recovering from mental distress. This study represents a combination of these two major areas, the critical role of caregivers and hope in recovery.

What do I hope to achieve with this research?

Having now completed the analysis, I would like to achieve some new insights in to the experiences of primary caregivers of a young person with psychosis and to also provide further understanding of the role of hope for caregivers, how their hopes can be nurtured and what may threaten their hopes.

What is my relationship to the topic being investigated?

In addition to the reflections above, I now feel I have a much closer relationship with the topic being investigated. I have an intimate relationship with the accounts of the caregivers I interviewed, and have further developed my awareness of the experiences of caregivers.

Who am I, and how might I influence the research I am conducting in terms of age, sex, class, ethnicity, sexuality, disability and any other relevant cultural, political or social factors?

Having conducted the analysis, one salient factor relates to my being a 34 year old male without children, which may have limited my ability to understand and empathise with the experiences of female parents.

How do I feel about the research work?

I have found the analysis process very tiring and intense. Given the large amount of data I collected, at times it became very difficult to keep focused on my objectives and I often began to feel a little ambivalent. Following the analysis, I am keen to begin writing-up as a way of processing my experiences during the analysis.

How will my subject position influence the analysis?

As a psychologist in clinical training I am likely to have a bias towards seeing participant accounts in terms of psychological processes and theory and I am also aware of my tendency to use psychological language rather than the terms and words used by caregivers themselves. Having an interest in hope may have biased my interpretations of the data towards looking for evidence supportive of the importance of hope.

How might the findings impact on the participants?

Following completion of my thesis report, I intend to send participants a summary of what was found. I would hope that this will provide some useful information for caregivers about some of the common struggles and challenges of caring for a young person with psychosis. I also hope that this might provide further encouragement to caregivers that steps are being taken to improve the support given to caregivers.

How might the findings impact on the discipline and my career in it?

I would like to think that the findings may provide some new insights into the experiences of caregivers, provide evidence for the need that clinical services specifically seek to assess and nurture the hopes held by caregivers, and provide evidence for how the hopes of caregivers can be fostered. In terms of my own career, I imagine that during my clinical work I will continually be aware of the need for hope in recovery and be attentive to developing hope. I have a personal preference for working systemically, and having conducted this study I will be more aware of the struggles and difficulties faced by caregivers and family members and to have an awareness of their support needs.

How might the findings impact on the wider understandings of the topic?

I would like to think that the findings will warrant publication, and from this I hope that the study can make a contribution to the existing literature on the experiences of caregivers within the context of FEP and how hope is important to them.

Appendix 9: Interview reflections

Interview 2

Reflections following interview

Participant was tearful throughout the interview. The interview evoked feelings of sadness in myself and I related aspects of her story to my own parent's experiences. My impressions were that the participant was very depressed. Following the opening question there was little need for further questions or prompts and my role as interviewer was minimal; I was simply required to actively listen. The participant was almost desperate to tell her story, leading me to think about the need of caregivers to routinely be provided with space and the opportunity to freely tell their stories and talk about their personal difficulties. I was also struck by the significant personal sacrifices the participant had made as a carer. Her description of recent family disputes and tension seemed significant in understanding the young person's psychosis; this led me to reflect on psychosis as an expression of difficulties within the relational context. I was particularly curious about the participant's description of relationships within her family having become much closer during and following her son's psychosis, leading to my having thoughts about what this may signify. Her son's hospital admission appeared to have been a very traumatic experience. Participant expressed not knowing what to do as a carer and not understanding her son's psychosis, leading me to reflect on the need of mental health services to be attentive to the need of caregivers to be provided with information and supported in trying to understand what had happened. Unlike previous interview, carer had not developed a coherent story of why her son had developed psychosis. Her story was often fragmented, containing many unprocessed emotions and unanswered questions. I developed a sense of services having failed to support her and her partner. Participant talked about the importance of hope during the interview without prompting, I interpreted this as suggesting that hope had been particularly meaningful for her.

Reflections during analysis

I was struck by how traumatic the participant's experiences had been and the intense emotions this had triggered. Sadness and despair and a context of difficult

relationships appeared significant themes. Participant appeared to lack an understanding of what had happened. She had found her son's hospital admission to be particularly traumatic, and witnessing her son in a great amount of psychological pain had been very difficult. The support received from her wider family network seemed limited. Participant was very keen to tell her story (?indicating need to process what had happened). Her emotions appeared very raw and unprocessed. There appeared to have been an adjustment of hopes for the young person – these being to have a normal life, to be happy and well. Some hopes were expressed for the future but these were tentative. Signs of personality returning and thinking about future seemed connected to hope. Relationships were described as having changed following psychosis; leading to my thinking about psychosis as an expression of communication and relationship difficulties within a family. During onset, participant very confused by what was happening. Her son was described as having regressed to a child-like state, leading parents to become very sensitive/over-involved out of concern and parental care.