

A thesis submitted to the University of Birmingham for the degree of  
Doctor of Clinical Psychology (Clin.Psy.D.)

## **VOLUME I**

# **RESEARCH COMPONENT**

### Literature Review

A review of the literature examining the impact of psychosis on spouses and  
partners

### Research Paper

The experiential impact of hospitalisation on families of young people with  
early psychosis: an Interpretative Phenomenological Analysis

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## **Overview**

This thesis is submitted in partial fulfilment for the requirements of the degree of Doctor of Clinical Psychology at the School of Psychology, University of Birmingham. It comprises of a research and a clinical volume.

### **Volume I**

Volume I is the research component of the thesis. It consists of two papers, a literature review and an empirical paper. The literature review, presented first, reviews the impact of psychosis on spouses and partners. The review identified psychosis as having an impact on the following areas: 1) the relationship itself, including relationship (dis)satisfaction and disruption, separation and divorce, sexual intimacy, and conflict and expressed emotion; 2) the individual partner, including changes in role, stress and burnout, objective and subjective burden, resilience, quality of life, and mental health; and 3) social and economic position, including social engagement, stigma, and finances. The psychosocial needs of partners are discussed, together with a range of implications for how services respond. The nominated journal for this review paper is 'Clinical Psychology Review'.

The empirical paper, presented second, is an interpretative phenomenological analysis of the experiential impact of hospitalisation on families of young people who are hospitalised with early psychosis. The research aimed to address the following: What is the meaning and impact of psychiatric hospitalisation for the young person's family? What was helpful and / or unhelpful for family members during this time? And, how do family members experience the hospitalisation process, from admission to discharge? Individual in-depth interviews were conducted with six relatives (parents) and Interpretative Phenomenological Analysis (IPA) was used to analyse the data, resulting in the emergence of five phenomenological themes. The findings identify families' perceptions of hospitalisation as being an understandably difficult, and at times, distressing experience exacerbated by the complexity of being a carer of an adult-child. Negotiating services and boundaries within the context of this relationship can contribute to feelings of exclusion and disregard by professionals and services. The recommendations that would arise from the present findings sit comfortably with the recommendations of current government mental health strategy with regard to how services

can face the challenges of engaging and including carers and equipping and enabling them to support their relatives with early psychosis. The nominated journal for this research paper is 'Psychosis'.

## **Volume II**

Volume II contains a series of Clinical Practice Reports (CPRs), based on work in clinical settings. CPR 1 presents the case of a female with depression, formulated from cognitive and psychodynamic perspectives. CPR 2 presents a small-scale service evaluation project exploring the extent to which Primary Care Mental Health Services are perceived by staff members to meet the needs of clients with Personality Disorders. CPR 3 presents a single case experimental design evaluating Rational Emotive Behavioural Therapy with a female teenager presenting with low mood and family relationship conflict. CPR 4 presents the case of a female with cognitive deterioration and Post Traumatic Stress Disorder, and offers a comprehensive neuropsychological assessment and cognitive formulation with treatment recommendations. CPR 5 (abstract only) details the psychological assessment, formulation, and recommended treatment pathway for a male with Learning Disabilities in a Medium Secure Forensic Setting with an Index Offence of attempted Murder.

NB: Throughout both volumes I and II all identifying names and information relating to clinical clients and research participants has been changed in the interests of their anonymity and confidentiality.

## **Dedication**

This thesis is dedicated to my family. To my dad, you are everything a father should be and all I hope to become; to my mum, you are my inspiration in all I do; to my brother, you gave me belief when I had none; and to Donna, for your selfless support and endless patience, you are my light.

How could anyone deserve to be so lucky?

This achievement in its entirety is dedicated to my Nan. I miss you.

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# **LITERATURE REVIEW**

## **A REVIEW OF THE LITERATURE EXAMINING THE IMPACT OF PSYCHOSIS ON SPOUSES AND PARTNERS**

## ABSTRACT

**Objective:** To review the literature addressing the impact of psychosis on spouses and partners, and to discuss the psychosocial implications for services.

**Method:** Major relevant databases were searched to identify relevant literature from 1994 to the present. Fourteen papers were considered appropriate for inclusion in the review on the following basis: the participant sample included spouses or partners of individuals experiencing psychosis; the aims of the research were to identify an impact of the illness on the partner and / or the partnership relationship; or to address a previously identified impact through psychological intervention.

**Results:** The review identified psychosis as having an impact on the following areas: 1) the relationship itself, including relationship (dis)satisfaction and disruption, separation and divorce, sexual intimacy, and conflict and expressed emotion; 2) the individual partner, including changes in role, stress and burnout, objective and subjective burden, resilience, quality of life, and mental health; and 3) social and economic position, including social engagement, stigma, and finances. The psychosocial needs of partners are discussed, together with a range of implications for how services respond.

**Conclusion:** Typically services focus predominantly on parent-carers; however there are clear differences in how spouses experience the illness of their partner compared to how other family members experience the same phenomena. Further research exploring the meaning of psychosis in partners' lives is warranted.

**Keywords:**

*Psychosis, Schizophrenia, Impact, Spouses, Partners, Literature Review*

# 1. INTRODUCTION

## 1.1 Context of literature review

Psychosis can be a debilitating condition for the individual mentally, physically, socially, and financially. It is also associated with economic costs to society, through loss of earnings and costs of care (WHO, 2001). Informal care-providers for those with psychosis have been the subject of research dating back to the 1950s (Clausen & Yarrow, 1955) particularly with a focus on the subsequent impact that the illness can have on them.

The commonplace view has been that family members, most notably parents, are the primary caregivers for individuals with psychosis in the community. As such, a wealth of studies can be identified in the literature examining the impact of psychosis on family members. The reader is directed to the following examples of recent reviews for a flavour of the work on family responses (Rose, 1996), burden (Awad & Voruganti, 2008), family work (Askey, Gamble, & Gray, 2007), and expressed emotion (Kymalainen & Weisman de Mamani, 2008). However, one group of caregivers have been omitted from much of the literature: spouses. This is curious because a significant minority (20-30%) of people with psychosis live in relationships (Jungbauer & Angermeyer, 2002). Crowe (2004) has highlighted the lack of research with this population:

*“It is almost impossible to find a review of the field, and yet psychiatric illness in its broadest sense is something which is very common...the partner is almost always adversely affected”.* (p. 309)

Why are spouses so often neglected in the psychosis literature? A frequent assumption is that because of the relatively early onset of the disorder and its related social deficits, people with psychosis would not be able to form and maintain permanent relationships (e.g. see Johnson, 2000; Melcop, 1997). Jungbauer and Angermeyer (2002) hold this in contrast to spouses of depressed patients, for whom it appears relationships play a far more important role, and consequently are better represented in the literature. Alternatively it has been posited that the notion of partnerships in psychosis is a relatively recent phenomenon made possible by advances in treatment and support services (Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004). A further hypothesis is offered by Zaumseil and Leferink (1997), who suggest that a “*modernisation of schizophrenia*” is occurring, whereby prejudices and resentment are being

socially eroded, making it increasingly likely that an individual with psychosis may be in a relationship.

It is clear from the existing literature that spouses of individuals with psychosis experience difficulties related to maintaining their sense of partnership, raising children, running the household, managing finances, and maintaining social contacts (Mannion, Mueser, & Solomon, 1994). A growing number of published studies are focusing on the impact of psychosis on the spouse. These studies vary in their focus, methodology, and epistemology; therefore the present paper attempts to review the current evidence base across the broadest possible spectrum.

## 1.2 Scope of review

This review considers international literature, over the past fifteen years, which examines the impact of psychosis on spouses and partners. Included in the reviewed literature are studies from peer reviewed journals and one published book. The limited number of studies published in this area warranted a wider search of the literature in order to generate appropriate content for a review. Studies reviewed originate from Europe, North America, and Asia. Evidently, experiences of mental health and the related impacts may differ across cultures and consideration of this will be raised during the review.

The current review aims to examine how psychosis affects the spouse or partner of the individual experiencing difficulties. The principal question of the review is: “what is the impact of psychosis on spouses and partners?” The review will therefore seek to identify how a psychotic illness impacts on partners and spouses, the partnership relationship that exists between the two individuals, and to identify the needs of partners.

The review will focus on a range of factors associated with:

- 1) The impact on the relationship itself, including relationship (dis)satisfaction and disruption, separation and divorce, sexual difficulties, and conflict and expressed emotion.
- 2) The impact on the individual partner, including change in role, caregiver stress and burnout, burden, resilience, quality of life, and the partner’s mental health.

3) The social and economic impact, including social engagement, stigma, and financial impact.

4) The consequences and implications for services given the identified psycho-social needs of partners.

### 1.3 Terminology

The diagnosis of schizophrenia generates controversy, and questions have been raised from critical perspectives regarding its reliability and validity (Bentall, 1990; Boyle 1990). Kuipers, Peters and Bebbington (2006) reflect that most of the refinement of the concept of schizophrenia occurred over the past century and a half, with significant contributions from German-speaking psychiatrists, such as Kraepelin and Bleuler. They suggest that it was conceived as an underlying *process*, which manifested itself in dramatic ‘positive’ symptoms (such as delusions and hallucinations) and in more insidious dysfunctions known as ‘negative’ symptoms (such as affective flattening, alogia, and avolition). Schizophrenia is still understood in these terms today. The current Diagnostic and Statistical Manual (DSM-IV) distinguishes between schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, brief psychotic disorder, shared psychotic disorder, psychotic disorder due to general medical condition, substance-induced psychotic disorder, and psychotic disorder not otherwise specified.

These categories are rarely employed in published studies, and the intricacies of diagnosis are communicated infrequently. Instead, common terminology is often limited to schizophrenia, schizo-affective disorder, or psychosis, and so throughout this review the term *psychosis* has been selected to encompass the range of difficulties above. An important point of language usage should be noted at this stage. If psychosis is accepted as a process or set of experiences then it could be argued that it is not appropriate to speak of an individual *with* psychosis or to use it as a diagnostic label. For purposes of brevity and clarity the reader should be advised to understand the term ‘*impact of psychosis*’ as referring to the consequential impact of being the partner of someone experiencing the phenomenology of psychotic experience.

The focus of this review is on the impact of psychosis on spouses and partners. Here ‘spouses’ are those individuals to whom a person continues to be lawfully married, regardless of cohabitation or separation status. The primary factor of concern is that the individual

maintains some degree of contact and provides some degree of care, such as psycho-social or financial.

‘Partner’ implies a long-term committed romantic relationship without a legal marriage. Throughout this review the term partner will relate to those individuals who are in a romantic relationship but not married by law, regardless of whether or not they are co-habiting. Reviewed studies vary in their conceptualisations of spouses and partners in terms of sexual orientation, co-habitation, divorce status / separation, and consequently comment is provided below (3.3 Assessing the quality of the studies) on the information provided regarding relationships.

‘Impact’ is a deliberately broad term aimed at capturing any aversive or non-aversive effects that psychosis has on spouses and partners. Drawing on general mental health literature, and published studies on the impact of psychosis on family members (predominantly parents), ‘impact’ includes burden, coping, stigma, relationship quality and satisfaction, and financial deficits. It should be noted that whilst the search was open to the inclusion of non-aversive impact, few examples of this were identified. In this way ‘impact’ is conceptualised differently to ‘meaning’, which may be expected to focus on experiential and phenomenological *understandings* of psychosis and its role in one’s life.

## **2. SEARCH CRITERIA**

### **2.1 Review Method**

The review includes all published journal articles that refer to the impact of psychosis on spouses and partners and their relationship with the implicated individual. The review includes international literature from the past fifteen years; this time frame was selected to provide a wide ranging but contained and manageable review set. An electronic database search was made of PsycInfo, CINAHL, EMBASE, and MEDLINE for published research papers. Searches were limited to English language studies in the years 1994 to 2009 to provide a fifteen year reference-frame. The search was designed to be as broad as possible and also included a review of reference lists of published articles to expand the search, although none was identified.

## 2.2 Search Terms

The search terms applied for each database were: [Psychosis (explode) OR schizophrenia (explode)] AND [partner\$ OR couple\$ OR spous\$ OR Marriage OR marital relationship\$ OR husband\$ OR wives] AND [impact OR burden OR coping OR stigma OR relationship quality OR relationship satisfaction OR caregiver burden], where \$ represents any word beginning with that prefix.

## 2.3 Search Outcome

After duplicates were removed, the search identified 40 references. After reviewing abstracts to establish relevance, 14 were selected for further scrutiny. These were considered appropriate for inclusion in the review on the following basis: The participant sample included spouses or partners of individuals experiencing psychosis (including all diagnostic variants described above in section 1.3); and the aims of the research were to identify an impact (psychologically, socially, or economically) of the illness on the partner and / or the partnership relationship, or to address a previously identified impact through psychological intervention.

# 3. OVERVIEW OF SEARCH FINDINGS

## 3.1 Range of studies identified

The search sought to identify studies from the past fifteen years that focused on the impact of psychosis on spouses and partners.

Of the 14 studies identified, ten employed quantitative methods (Angermeyer, Bull, Bernert, Dietrich, & Kopf, 2006a; Angermeyer, Kilian, Wilms, & Wittmund, 2006b; Bruckner, Peter, Rufer, Bandelow, Dahme, Hand, & Muller-Pfeiffer, 2008; Croake & Kelly, 2002; Crowe, 2004; Kumar & Mohanty, 2007; Laidlaw, Coverdale, Falloon, & Kydd, 2002; Wittmund, Wilms, Mory, & Angermeyer, 2002; Mannion, Mueser, & Solomon, 1994; Phelan, Bromet, & Link, 1998), and four employed qualitative methods (Hardcastle, Kennard, Grandison, & Fagin, 2007; Jungbauer & Angermeyer, 2002; Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004; Mannion, 1996).

The scope of the quantitative studies was varied and focused on spousal quality of life, caregiver burnout, expressed emotion, marital adjustment, impact of mental illness on spouses, caregiver stress, spousal mental illness, psychoeducational programmes, and stigma. Of the qualitative references, one was a book focusing on service users' experiential narratives of hospitalisation, and three were peer-reviewed journal articles focusing on spousal burden and resilience. Epistemological perspectives offered include narrative and phenomenological.

The literature search identified seven studies (in German, Chinese, and Japanese) that were not translated to English language, which focused on spousal coping strategies (Jungbauer & Angermeyer, 2003), financial impacts (Wilms, Mory, & Angermeyer, 2004; Mory, Jungbauer, Bischkopf, & Angermeyer, 2002), caregiver burden (Wittmund, Nause, & Angermeyer, 2005), spousal mental illness (Zhao, Yang, Liu, & Xu, 2005), quality of life (Tan, Liu, & Li, 2001), and spousal perceptions of schizophrenia (Nobuyuki & Shiari, 1997). No studies in English had a primary focus on financial implications.

Overviews of the design, sample, and analysis can be found in Appendix 1. The following section examines the range of theoretical approaches in the identified studies.

### 3.2 Theoretical considerations

The studies considered in the current review approach the area from exploratory perspectives. No studies explicitly offer a theoretical position, but Kumar and Mohanty (2007) draw on psychodynamic influences to explain coping styles of spouses, and Croake and Kelly (2002) describe intervention from an Adlerian perspective. In the absence of theoretical underpinnings, it is perhaps useful to consider a number of potential theories that might be used in an attempt to describe what the research of the current review papers set out to achieve and the processes that they attempt to describe.

When considering theoretical positions that might meet this aim, a number of plausible options present themselves. For example, the processes described in the current research set might be explained by drawing on the Systemic Couples Literature (e.g. Gurman & Jacobson, 2002; Halford & Markman, 1997) or the Family Interventions literature (e.g. Milkowitz, 2004; Fadden 2009). However, such approaches might be considered to view the spouse / partner's needs as primarily important in the context of the individual with psychosis. Instead,

an alternative set of perspectives are offered for consideration in this review: Hopper's (2007) application of the Capabilities Approach (CA) to the recovery model in psychosis; and Self-Determination Theory (SDT) (Deci & Ryan, 1995, 2002).

Central to these theoretical positions is the importance of viewing individuals (i.e. the spouse/partner) 'in their own right' and, in the current context, as having needs separate to those of their ill partner. For example, Hopper's (2007) work and that of the recovery model, is primarily focused on describing, at a general level, the processes that are at work or that are important for the individual. It is considered that this work can be applied effectively to spouses. Examples of research where this thinking is applied are offered in the field of addictions, for example Coppello, Velleman & Templeton (2006) and Coppello, Williamson, Orford and Day's (2006) work on social network's, which stress the need for interventions to be aimed at responding to the needs of family members affected by drug and alcohol problems in their own right. Here Hopper's framework and SDT would view the spouse not as part of a systemic problem, but as having related and distinct needs. Further explanation and consideration of how these theoretical perspectives might be applied to this area is offered in the discussion.

### 3.3 Assessing the quality of the studies

Assessing the quality of the studies is complicated by the scope and variation within the identified articles. The current review set varies in terms of the ontological, epistemological and methodological approaches adopted. The research to be reviewed focuses upon the impact of an 'illness' and not an intervention, therefore the 'gold standard' of randomised control trial (RCT) is unlikely to be appropriate in the quantitative literature in this area, and is notably absent. The qualitative literature in the area is burgeoning and authors are adopting new methods of analyses as these methods increase in popularity.

The scope of the studies made it difficult to make direct quality comparisons. To assist with this, a division was made between quantitative and qualitative research. From each paper the following were extracted and can be found in tables 1 and 2 in the appendix:

- Size and demographic qualities of the sample (particularly gender and ethnicity)
- Description of relationship (e.g. married, engaged, cohabiting, apart)

- Duration of relationship
- Whether the onset of the illness was prior to or during the current relationship

Quantitative studies were compared using the following indicators of quality, informed by Sale and Brazil (2004):

*Truth Value (Internal Validity)*

- The presence of a control or comparison group
- The method of data collection and robustness of data analysis

*Applicability (External Validity/generalisability)*

- Area of impact addressed by the research (Statement of purpose)
- Whether the method allows for replication (Description of process)
- Whether a sound rationale was provided
- The presence of a theoretical perspective
- The size and demographic qualities of the sample (situating the sample)
- Inclusion / exclusion criteria documented
- The use of standardised outcome measures
- Presence of a long term (6+ month) follow-up

*Consistency (Reliability)*

- Standardisation of observers (e.g. Blinding procedures)

Qualitative studies were compared using the following indicators of quality, informed by Sale and Brazil (2004):

*Truth Value (Credibility)*

- Systematic analysis of the data (including credibility checks)
- Whether assertions were grounded in examples

*Applicability (Transferability/fittingness)*

- Area of impact addressed by the research (Statement of purpose)
- The coherence of the epistemological position
- Whether a sound rationale was provided
- The relevance of theoretical perspective adopted
- The size and demographic qualities of the sample (situating the sample)
- Whether the method allows for replication (Description of process)
- Reflexivity considerations

*Consistency (Dependability)*

- External audit of process

*Neutrality (Confirmability)*

- Statement of researchers assumptions

The results are presented in tables 1 and 2 below. The quality assessment has been used in the structure of this review; therefore the review concentrates on the higher quality literature, such as the quantitative work offered by Angermeyer et al. (2006) and the qualitative research of Jungbauer and Angermeyer (2002) and Jungbauer et al. (2004). The impact of psychosis on spouses and partners will be considered in the following section.

Table 1: Quality assessment of quantitative studies

		<b>Angermeyer et al. (2006)</b>	<b>Angermeyer &amp; Bull et al. (2006)</b>	<b>Bruckner et al. (2008)</b>	<b>Croake &amp; Kelly (2002)</b>	<b>Crowe (2004)</b>	<b>Kumar &amp; Mohanty (2007)</b>	<b>Laidlaw et al. (2002)</b>	<b>Wittmund et al. (2002)</b>	<b>Manion et al. (1994)</b>	<b>Phelan et al. (1998)</b>
Truth Value (Internal Validity)	Control group	√									
	Comparison group	√	√		√			√	√	√	√
	Systematic analysis of data (P values and confidence intervals stated)	√			√		√	√	√	√	√
	Statement of purpose (area of impact addressed)	√	√	√	√	√	√	√	√	√	√
Applicability (External Validity/ generalisability)	Description of process (Replicable)	√	√	√	√	√	√	√	√	√	√
	Rationale provided	√	√	√	√	√	√	√	√	√	√
	Relevant theoretical perspective provided				√		√				
	Demographic qualities of sample provided (situating the sample)	√	√	√	√		√	√	√	√	√
	Inclusion /	√	√	√	√		√	√	√	√	√

	exclusion criteria										
	Long term follow up (6+months)				√					√	√
	Standardised outcome measures	√	√	√	√		√	√	√		√
	Standardisation of observers				√						
Consistency (Reliability)											

Table 2: Quality assessment of qualitative studies

		<b>Hardcastle et al. (2007)</b>	<b>Jungbauer &amp; Angermeyer (2002)</b>	<b>Jungbauer et al. (2004)</b>	<b>Manion (1996)</b>
Truth Value (Credibility)	Systematic analysis of data		√	√	
	Triangulation and credibility checks		√	√	
	Assertions grounded in examples (quotations)	√	√	√	√
Applicability (Transferability/fittingness)	Statement of purpose (area of impact addressed)	√	√	√	√
	Coherent epistemological position		√	√	
	Rationale provided	√	√	√	√
	Relevant theoretical perspective provided				
	Demographic qualities of sample provided (situating the sample)	√	√	√	√
	Description of process (Replicable)		√	√	√
	Reflexivity considerations			√	
Consistency (Dependability)	External audit of process				
Neutrality (Confirmability)	Statement of researchers assumptions		√	√	

## **4. WHAT IS THE IMPACT OF PSYCHOSIS ON THE PARTNERSHIP RELATIONSHIP?**

This section attempts to explore what the literature tells us about the impact of psychosis on the partnership relationship. The areas to be considered include relationship satisfaction and disruption, relationship maintenance with reference to separation and divorce, the sexual relationship, and relationship conflict.

### 4.1 The impact on relationship satisfaction (dissatisfaction and disruption)

Marital dissatisfaction and disruption is often present in relationships where one partner (or both) experience mental ill health (e.g. Fadden, Bebbington, & Kuipers, 1987). In Mannion's (1996) review of resilience and burden in spouses of people with mental illness, she highlights examples of the disruption experienced by spouses with partners experiencing psychosis. This includes frequent arguments, someone leaving, disruption outside the household, and work-related disruption due to illness in the employed spouse. Moreover, in Jungbauer and Angermeyer's (2002) qualitative, phenomenological exploration of the effects of psychosis on parents and spouses, they identify how the insidious nature of the illness leads to "disorder-conditioned alterations" of the implicated spouse, leading to a direct impact on relationship satisfaction for the spouse. They cite changes to the ill partner - including mood, behaviour and personality, increased fatigue, loss of interest and motivation, and loss of humour and self-confidence – which are experienced as losses by the spouse. Additionally, spouses reported that in their everyday lives they felt "strained by sorrows", and suggested that psychosis is perceived as a latent threat during the non-acute phases, "hanging like the sword of Damocles over everyday family life". Jungbauer and Angermeyer's (2002) sample further identified aspects of the illness that generated dissatisfaction and disruption in their relationships. Participants described how it became harder to separate the person from the illness. It was stressful to determine whether the illness or the individual's disposition was to be "blamed for problematic behaviour". For example:

*"The biggest difficulty for me personally is that his unpredictability is hard to limit. You can't really say: 'That is due to the disposition or that is due to the disorder.' It's*

*like a blur sometimes. And that really is the most difficult and hardest thing.” (p. 115).*

These ideas are supported in Hardcastle et al.’s. (2007) edited series of service users’ experiential narratives of hospitalisation. A compelling narrative offered by ‘Charlotte’, the wife of the hospitalised ‘Peter’ discusses how their relationship was disrupted by periods of hospitalisation, and describes how the man she “knew and loved seemed to disappear under a great cloud of bizarre ideas, hallucinations and strange mood swings.”

The amount of disruption and dissatisfaction experienced by a spouse may also depend, in part, on their preparedness for what may lay ahead. In Jungbauer et al.’s (2004) qualitative study of subjective burden in spouses of people experiencing psychosis, they suggest that when a partnership is entered into after the onset of the illness, the spouse of the affected individual may not be aware of the risks of relapse and cannot therefore anticipate the associated burdens. They further suggest that even when the spouse “knows in theory” of their partner’s risks, the burdens are often underestimated. Jungbauer et al. (2004) suggest that a relapse of a patient whose illness has probably existed for many years can be just as burdening for the spouse as a primary onset of the illness.

A picture of marital dissatisfaction and disruption directly resulting from psychosis is described in this literature, but Jungbauer et al. (2004) raise an important concept regarding the role that psychosis and mental illness can play in relationships. In their qualitative interviews with 52 spouses of people experiencing psychosis, they identified that participants who were ill themselves not only reported limitations, but also advantages of living together with the patient. Participants commented that where both partners have mental ill health it can be positive and provide mutual understanding and support:

*“I have to show consideration for my wife, she’s got the same thing I’ve got – schizophrenia. Sometimes I notice that she can’t take too much...we lead a very quiet life... we don’t get distressed and so on.” (p. 671)*

Whilst some positive elements can be derived from the shared experience of two partners with mental ill health, psychosis can be a great source of disruption and dissatisfaction as the following quote from an interviewee of Jungbauer et al. (2004) suggests:

*“The illness has changed him a lot and as a result also the family, children, and myself, and just the whole surroundings. I’m sure it will never be like it has been in the past.” (p. 672)*

Finally, in their study of structured group couples therapy, Croake and Kelly (2002) applied an Adlerian based psychoeducational approach to develop social coping skills in female spouses of males experiencing psychosis. They identified that marital adjustment and satisfaction was observed to increase in the spouses. This research would indicate that some of the impact that psychosis has on marital satisfaction can, to an extent, be addressed through structured psychotherapy.

#### 4.2 The impact on the maintenance of the relationship (separation and divorce)

The difficulties and complexities generated by living with a partner experiencing a severe and enduring mental health condition such as psychosis inevitably raises an emotionally charged decision: relationship maintenance versus separation.

Angermeyer et al. (2006) cite a finding that “most partners consider separating from their ill partner during illnesses”. Another of their principal findings was that those who opted against separating from their partner seemed to have accepted the illness as a component of their shared history and were therefore trying to cope with it as best as possible. As a result Angermeyer et al. (2006a) explain that most partner-carers experience less burnout than nurse-carers. This point raises an interesting consideration of the reviewed studies, in that most studies are biased because the participants remain together. Much less is therefore known about partners for whom the impact of the illness was so great that the relationship was dissolved. These sentiments are echoed by Jungbauer and Angermeyer (2002), who highlight that their interviews were conducted with spouses who had decided *in favour* of maintaining their relationships and therefore it is not possible to make data-based comments about the conditions that bring about separation or divorce.

In their phenomenological study Jungbauer and Angermeyer (2002) highlight that relationships with people with psychosis can be described as “fragile partnerships” where the joint perspective in life is called into question. They suggest that separations, when they do occur, are toward the middle to long term. Initially spouses stay with their partners and the relationship is seldom questioned. However this solidarity may give way during the further

course of the illness when the spouse has to revise their expectations. In this way it can be seen that the ‘rules change’ and divorce becomes a viable option:

*“The fact that partnerships are relationships filled with presumptions... that no longer apply under certain circumstances plays a crucial role... a separation is considered if in the spouse’s opinion basic premises of the relationship are no longer present.” (p. 119)*

Jungbauer and Angermeyer’s (2002) research also identifies that the question of separation becomes more urgent when there is the presence of physical violence or if the non-ill spouse’s mental health begins to deteriorate as a consequence.

Some writers, including Melcop (1997, cited in Jungbauer, 2002), have presented a negative view of relationships with people with psychosis, stating that they will break up “almost as a rule”. Indeed those who have chosen to remain in relationships have described them as a “marriage from hell” (Jungbauer & Angermeyer, 2002). However, Jungbauer *et al.* (2004) advocate that with increased support, relationships can be maintained, although the majority of intervention programmes are tailor-made to suit parent-carers’ needs and as such spouse-carers can rarely access the required support.

Participants in the Jungbauer *et al.* (2004) study provide a useful insight into some of the factors that are important in maintaining relationships, including the following: traditional social norms regarding marriage and partnership, religious beliefs, beliefs in the insolubility of marriage, belief that in the reverse case (i.e. they had a psychotic illness) the partner could be reliant on their spouse, and obligation.

#### 4.3 The impact on the sexual relationship

From the existing literature three aspects of psychosis appear to be implicated in the impact on a couple’s sexual relationship: hospitalisation, medication effects, and disintegration of intimacy and relationship bonds.

The edited narrative offered by ‘Charlotte’ in Hardcastle (2007) reflects on two of these areas, the impact of hospitalisation and the effects of medication on her husband’s sexual performance. ‘Charlotte’s’ narrative describes how the hospital’s physical environment prevented intimacy:

*“As for making love, that was out of the question. We couldn’t even sit side by side and have a cuddle, with just one hospital chair in the room. When... I did join him precariously in his single bed, we felt like naughty school children, with one eye constantly on the door in case any staff should see us.” (p. 89)*

She also highlights how staff were unresponsive to her needs to discuss intimacy and consider their needs as a couple, leaving her feeling guilty about her emotional and physical needs. Additionally Charlotte describes how when she was intimate with her husband he continuously experienced difficulties ejaculating as a result of the anti-psychotic medication.

Jungbauer and Angermeyer (2002) identified similar difficulties in their qualitative sample, suggesting that sexual impairments brought about by medication can lead to “emotional estrangement” of spouses. This is a strand of the research that Jungbauer et al. (2004) develop further, stating that “joint sexuality can be permanently spoiled by schizophrenia”. The author’s describe how sexual interest and pleasure for the ill person are hindered by the side effects of medication. They cite examples such as increased weight gain as a factor in leading the person to feel unattractive.

The final aspect of psychosis that appears to be implicated in impacting on a couple’s sexual relationship is the disintegration of intimacy and relationship bonds caused by relationship disruption. Jungbauer et al. (2004) suggest that sexual relationships are impacted on by atmospheres of marital discord, tensions, decreased communication, increased conflict and increased marital dissatisfaction. Crowe’s (2004) review of couples and mental illness adds support to this, stating that in many cases the individual with psychosis will experience a diminution of their sexual desire as a direct result of the negative symptoms of the illness. This diminution is often accepted by the partner, but, in cases where it is not, this causes increased conflict and stress, which may in turn increase the patient’s symptoms.

#### 4.4 The impact on relationship conflict

The existing literature appears to indicate that psychosis is directly associated with increased relationship conflict. For instance, in their study of spousal burden, Jungbauer et al. (2004) reported that, following the onset of the illness, some of their sample found their partners to be moody, irritable, and solitary, whereas others found them to be moaning, contentious or even vicious and aggressive. Where the ill spouse had a tendency toward aggressive and

provoking behaviour, escalations of conflict were common (see also Crowe, 2004). Some debate exists regarding the directional association between psychosis and conflict. Is the illness itself responsible for increased conflict (as in the above examples) or does the presence of a conflictual relationship exacerbate (or directly lead to) a psychotic illness? This is a question sometimes posited in the Expressed Emotion (EE) literature (see Schriebe, Breier, & Pickar, 1995, for further exploration of this concept).

EE is a construct based on how relatives talk about the patient. Relatives are classified as high in EE if they make more than a specified number of critical comments or show signs of hostility or marked emotional over-involvement (Bruckner et al., 2008). It should be noted, therefore, that EE as a concept is broader in scope than conflict per se and is associated with bidirectional, mutually influential cycles of interaction between relatives and patients (Milkowitz, 2004). Whilst there is a large evidence base focusing on EE in family members, less research has focused specifically on partners. In Bruckner et al.'s (2008) study, healthy and happily married partners (HHP) were compared with partners of people experiencing psychosis on measures of EE. The principal finding was that the clinical comparison group displayed greater levels of EE than the HHP group. Additionally, however, it was found that following intervention, the clinical comparison group still displayed higher levels of EE than the HHP group. The authors suggest that the high EE scores seen in spouses of psychosis patients might be explained by the stress caused by the process, and associated difficulties such as unemployment and lack of social support. This would stand in contrast to the concept that high EE attitudes are the cause of, or exacerbate, the illness / relapse.

In their study of spousal burden of care in an Indian sample, Kumar and Mohanty (2007) develop ideas from their earlier unpublished study that investigated burden and psychodynamic defence mechanisms in female partners of people experiencing psychosis. They identify that the use of projection in female spouses is associated with greater relationship conflict. In their study, projection includes defences that justify the expression of aggression towards an external object (the spouse). The female spouses in the study typically reported that the patient himself was responsible for the illness and lacked insight. They also blamed other family members for a lack of support, and also stated that being female they could not offer timely and efficient support, and that the cost of treatment was too great. Such attributions relating to the patient, family members, and other aspects of the environment are

considered characteristic projection defences, which spouses use to mitigate their distress. Notably this study is based on a culturally specific and small Asian sample, and has not been attempted with European or North American samples.

## **5. WHAT IS THE IMPACT OF PSYCHOSIS ON THE PATIENT'S PARTNER?**

The focus of the following chapter moves away from the impact of psychosis on the dyadic relationship and instead concentrates on the effects experienced specifically by the patient's partner. The areas to be considered include role changes experienced by the partner, stress and burnout, burden, resiliency, personal quality of life, and the partner's own mental health.

### **5.1 Role changes**

The primary role change experienced by partners of those with mental illness is a shift from a partnership of mutual equality to one of caregiver and recipient. According to Angermeyer et al. (2006a) this relationship is characterised by providing informal care at home until care becomes impossible or the individual is hospitalised. After the hospital stay or when the individual's health improves, there is a reintegration into the partnership and care is resumed at home. There are no fixed times for care; instead the partner must now be available as the need arises, and respite such as holidays or breaks is often impossible. Angermeyer et al. (2006a) suggest that this caregiver role only terminates with the ill person's recovery but the fear of relapse is continuous.

Wittmund et al.'s (2002) study of depressive disorders in spouses of mentally ill patients conveys the burden of new role. They describe how many spouses talk about their mentally ill partner in terms of "having another child" instead of a friend, husband or lover. Wittmund et al. also assert that the experience of life living with a mentally ill partner is often very different from how life should develop. They further cite losses often associated with this newly adopted carer role, including loss of expectations about the partnership, limitations in their own career, loss of social acceptance, and limitations in social and leisure activities.

Jungbauer and Angermeyer (2002) pick up these themes in their qualitative study of spousal and parental burden. They highlight how when one half of a couple experiences psychosis, the original definition of the relationship is called into question, as the implicated partner is perceived as “altered and strange”. Participants in their study identified the considerable changes that occur including the necessity often to redefine the division of roles in the relationship. This reorganisation can concern employment, household tasks, and children’s education, usually with the spouse of the patient taking over an additional range of responsibilities. The previous symmetric role division before the onset of the disorder inevitably leads to the spouse finding themselves permanently in a leading or supporting position. Interestingly, participants in Jungbauer and Angermeyer’s sample identified how caring for a heavily impaired person, as burdensome as it may be, imparted structure and meaning to the spouses’ lives. When this structure was disrupted for an extended period, for instance through hospitalisation, the spouses reported experiencing a vacuum and loss of meaning.

In Mannion’s (1996) review of caregiver burden and resilience she expands on the difficulties experienced by spouses of psychotic patients when children are involved. She cites Rolland (1994) who suggested that, when a parent develops a psychotic illness during the highly cohesive child-rearing phase of development, it severely taxes the family’s ability to stay on course. The impact of the illness is likened to “the addition of a new infant member”, one with special needs who competes with the real children for the potentially scarce family resources. In Mannion’s own interviews with participants, however, an interesting spousal coping strategy was identified. In an alternative to the concept of embracing a new care-giver role, Mannion (1996) identified spouses who did not accept their role as a carer, and remained focused on being a *spouse*.

*“I DO NOT consider myself a care-giver. If I saw that as my role I could not be in this marriage. I have a need to go and do more than he does, so I do. I’ve learned to reassure him I will come back.” (p. 21)*

## 5.2 Caregiver stress and burnout

In their study comparing burnout of spouses to that of psychiatric nurses, Angermeyer et al. (2006a) reported somewhat unexpected findings. Less than one third of their spouse sample

reached burnout levels with regard to emotional exhaustion, depersonalisation, and personal accomplishment. Moreover no significant association was found between duration of caregiving and degree of burnout. These results are explained by the authors as a function of the partners coming to accept the illness as a component of their shared mutual history.

Jungbauer and Angermeyer (2002) offer some additional qualitative support for the above findings, suggesting that, with an increasing duration of shared experience of the disorder and better information, partners are more able to better master the psychotic experiences of the disorder; they are better equipped to find help and support; and can better interpret early signs of relapse and seek professional help. Additionally, Jungbauer and Angermeyer (2002) suggest that the greatest period of stress is associated with the development phase of the illness, typically seen in late adolescence. Therefore it is most commonly the parents who are present for the illness onset rather than partners.

Laidlaw et al. (2002) attempt to fill some of the gaps in the existing research in this area by investigating stress and burden in caregivers living with *or* apart from the patient. This research utilises a sample mostly of parents but includes sizeable number of partners. It is included in the current review as this study represents the only research examining the effects of partners not living together with the person experiencing psychosis. The primary findings were that caregiver stress is the same whether the carer lives together with, or apart from, the patient although the sources of stress differed. When living with the ill individual the following sources of stress were reported: lack of communication from the patient, medication concerns, therapy and professional care concerns, and the dearth of information given directly to them from professionals. When living apart, participants were not confronted with irritating aspects of behaviour such as a lack of contribution to the household but this was countered by worry about what was happening to them on a day-to-day basis.

In Mannion et al.'s (1994) study, designing psychoeducational services for spouses of severely mentally ill individuals, they identified that high spouse distress was associated with high negative attitudes toward the ill partner. Importantly they identified that increasing spousal knowledge of the illness through psychoeducation did not reduce negative attitudes toward the ill partner, however reducing spouse distress through support had a positive impact on attitudes.

### 5.3 Burden

The area of burden has been studied in great depth with respect to carers and relatives, however with reference to psychosis the focus has tended to be on parents and family of origin (see Awad & Voruganti, 2008). Less is understood about the burden experienced specifically by spouses.

In writing a review of the impact of psychosis on spouses, separating burden as an independent sub-section is somewhat difficult. Indeed all the sub-sections and chapters of this review have implicit within them the implication of burden. Jungbauer et al. (2004) summarise this point neatly in their qualitative exploration of subjective burden in spouses of people experiencing psychosis:

*“Spouses not only face illness specific burdens but also burdens resulting from their partnership and family roles... [psychosis] seriously affects the couple’s relationship, the family, and the spouses own life. The chronic burdens of everyday living can profoundly reduce the quality of life and the subject’s satisfaction with the partnership”. (p. 665)*

Another study in the current review set to specifically focus on spousal burden of care in psychosis is that of Kumar and Mohanty (2007). The authors identified that female partners experienced greater burden than did male partners of psychotic patients. The explanation offered for this finding is that typically female spouses feel more anxious, tired, frustrated, isolated, and experience greater workload. Besides full domestic responsibilities, the illness in the husband places additional financial, caring, treatment and social responsibilities on the female partner. However, as highlighted above this study is based on a culturally specific and limited Asian sample, and transferability is inevitably limited.

### 5.4 Resilience

Partners’ resilience is considered to mediate the impact of psychosis. In Jungbauer and Angermeyer’s (2002) qualitative research, they discuss evidence that those partners who make use of the greatest variety of coping strategies are most confident that they can deal successfully with their strained living situation. In contrast defensive coping strategies such as avoidance or resignation are associated with negative feelings, depression and grief.

Conversely, relativist coping strategies such as optimism and acceptance are associated with lowest levels of stress.

Additionally, in Mannion's (1996) review of resilience and burden in spouses she describes the importance of partner resilience, particularly where children are involved. Amongst the most prominent resilience concepts identified by participants were patience and tolerance. Mannion also identified that participants felt that their coping skills were enhanced as the duration of the illness grew. Participants attributed these developments to their acceptance of the illness; this finding would support the above, but also findings from the burnout literature (see section 5.2).

### 5.5 Quality of life

Similarly to section 5.3, separating quality of life as an independent sub-section is again difficult. All areas addressed in this review are likely to impact a partner's quality of life, however Angermeyer et al. (2006b) specifically pick up on these ideas in their study of quality of life in spouses of mentally ill people. The authors suggest that psychosis has been shown to have a greater impact on a spouses' quality of life than other mental illnesses such as affective disorders and their research supports this finding. Additionally it was observed that compared with healthy controls, the quality of life of spouses of mentally ill individuals was lower in the domains of psychological well-being and social relationships. Importantly it was identified that the higher the level of functional impairment of the ill partner, the lower their spouse's quality of life was.

Perhaps in contrast to the above findings however, Jungbauer and Angermeyer (2002) distinguish between acute and chronic stages of psychosis. They suggest that partners' quality of life is most affected during the chronic phase, when spouses do not have the acute symptoms of the illness to manage but instead live with the burden of potential relapse.

A further alternative and contrary view is offered by Jungbauer et al. (2004), who identify that quality of life can in fact increase through mutual understanding and support in situations where both partners have mental illness. A shared mutual lifestyle is often considered a satisfying way of life appropriate to the illness.

## 5.6 The partner's mental health

Given the evidence thus far described, it is unsurprising that the partners of those experiencing psychosis may themselves experience mental ill health as a consequence of their experience. In Jungbauer and Angermeyer's (2002) qualitative study of effects of psychosis on parents and spouses, they suggest that a progressive loss of emotional strength leads many caregivers to find themselves increasingly sensitive and emotionally unstable. Furthermore they suggest that some caregivers suffer from a permanent depressive mood matching the clinical presentation of dysthymia. One participant describes her experience thus:

*“My nerves couldn't take it anymore... I was just lying in bed crying...Now I'm so far gone, I am receiving psychiatric attendance too. And I have days when everything is too much for me”. (p. 116)*

This finding is quantitatively supported by Wittmund et al. (2002) who found that the likelihood of a spouse experiencing depression is significantly increased in partners of people with psychosis than in the general population. Additionally, it was identified that female partners appeared to be more at risk of mental ill health than male partners. An important consideration raised by Wittmund et al. regarding prevalence rates of psychiatric disorder in spouses relates to where and when the partners met. Whether patients get to know each other in circumstances that increase the probability of meeting a person suffering from psychiatric illness may have an important influence on the prevalence of psychiatric disorders in their spouses. This concept is referred to as the “assortive mating hypothesis” and is offered as an explanation for the elevated rates of psychosis observed in partners of psychosis patients.

What is more, in their qualitative spousal burden study, Jungbauer et al. (2004) suggest that where a partner has their own mental health difficulties (for instance through assortive mating), this can actually serve as a protective factor for them and the relationship. The authors suggest that on the basis of the psychiatric crises that the partner has themselves experienced, they are more capable of understanding their partner's experiences, view them as less threatening, and have more realistic expectations of the relationship.

## **6. WHAT IS THE SOCIAL AND ECONOMIC IMPACT OF PSYCHOSIS ON THE PATIENT'S PARTNER?**

The following chapter seeks to illuminate what the literature informs us of the social and economic impacts experienced by the partners of individuals experiencing psychosis. Specific focus will centre on the limitations experienced regarding social engagement patterns, the impact of stigmatisation, and the financial implications of a severe and enduring mental health problem.

### **6.1 Social engagement**

In their study of the quality of lives of spouses of mentally ill people, Angermeyer et al. (2006b) identified a number of reasons why social engagement is affected. Primarily they assert that the nature of time consuming care-giving inevitably leads to reduced social recreation time. However, they also suggest that worries about negative reactions from other people, either directed at the individual experiencing psychosis themselves or those caring for them, may negatively impact on spouses' social relationships. Importantly, they highlight that the more impaired the person is the greater the social impact is likely to be; this is also associated with spouses' perceptions of reduced quality of life.

In their qualitative study of perceived burden in spouses of psychosis patients, Jungbauer et al. (2004) focussed on social relationships outside of the family and found that participants reported a gradual loss of social contacts as their partner's illness progressed. They suggest that this commonly occurs when pre-existing acquaintances withdraw from the patient and their family, where the patient and their spouse are no longer able to invest energy in maintaining social contacts, and also when they fear potential stigmatisation. Spouses reported being "deeply affected" by a loss of social contacts.

In their study of study of depressive disorders in spouses, Wittmund et al. (2002) also discuss stigmatisation fears as a reason for a reduction in social engagement. They suggest that partners may feel ashamed or afraid to seek support, fearing what others will think about them and their partner. They suggest such fears often lead to self-imposed avoidance of social situations in an attempt to avoid questions from others.

Similarly Mannion's (1996) review also cites evidence where spouses have actively sought to conceal their partner's illness and employed strategies such as moving house or cutting off existing relationships.

## 6.2 Stigma

Whilst stigma has been linked with a reduction in the social activity of spouses of individuals experiencing psychosis, it is also thought to have a more pervasive impact on their lives. One area of particular difficulty experienced by spouses is the process of hospitalisation. Participants in Jungbauer et al.'s (2004) study describe how enforced hospitalisation is often accompanied by distressing scenes involving medical staff and police. Participants described this as embarrassing and humiliating, and described feelings of guilt, shame and failure related to societal prejudices about mental illness.

Phelan et al. (1998) take a more in-depth examination of the impact of stigma on families and spouses. They identified that spouses may be exposed to greater levels of stigma than parents because their social networks and those of their spouse overlap to a greater extent, however their findings indicated that parents and spouses experienced comparable levels of stigmatisation. However, the authors did find that spouses perceived higher levels of avoidance by their social contacts than did parent carers. An interesting finding offered by the authors is that higher educational attainment and higher socio-economic status (SES) of the spouse is associated with greater perceptions of avoidance and stigmatisation. The authors suggest that this may be interpreted in various ways: higher status individuals may be more perceptive to actual rejection; they may be overly sensitive and falsely interpret others' behaviour; or more highly educated acquaintances may react to mental illness in more stigmatising ways.

## 6.3 Financial impact

The existing evidence is limited in regard to the financial impact of psychosis on partners. A number of international studies have been published focusing specifically on this area but are not available in English (see Wilms, Mory, & Angermeyer, 2004; Mory, Jungbauer, Bischof, & Angermeyer, 2002).

Of the current review set, Angermeyer et al.'s (2006b) findings indicated that spouses' material quality of life was unaffected by their partners' illness. However, in their study of spousal burden of care, Kumar and Mohanty (2007) suggest that a greater financial impact is experienced if the implicated partner is male. Whilst this may reflect the social context of their Indian sample, Mannion (1996) reviews literature where this finding has been repeated with European and North American samples. In addition, Mannion suggests that reasons for financial burden experienced by spouses include the income reduction due to the unemployment of one partner, ineligibility of married couples for financial benefits that would be available to single persons with mental illness, and the burden of additional costs incurred through paying for external services such as childcare. Mannion suggests that such financial difficulties can severely compromise the dreams that many people bring to marriage such as home ownership, travel, early retirement, or funding their children's university education.

## **7. DISCUSSION AND IMPLICATIONS**

Based on the evidence reviewed it is apparent that an individual's psychotic illness can have a significant and enduring impact on their partner and the relationship that they share together. The existing research indicates that whilst there are multiple areas where the impact of the illness is observed, these areas have a complex interactive nature which inevitably magnifies the pervasive and deleterious effects of the illness. From the studies reviewed it is possible to identify a number of psychosocial needs of service users (patients and partners), which inevitably have implication for how services respond.

### **7.1 Psychosocial needs of (people) Service users**

In Charlotte's narrative (in Hardcastle et al., 2007) she describes how, in hospital settings, the concepts of healing, comfort and recovery are inextricably linked to care-plans, MDTs, medication and therapeutic outcomes, and how "one's very humanness is professionalised". Perhaps above all people need to be treated as people and not depersonalised, professionalised and labelled as "service users". In this way human needs such as sexuality and intimacy may come to be viewed as more central to appreciating the needs and experiences of the partners of people with psychoses.

What is evident is that spouses require support through a difficult and confusing time. The literature identifies that partners ask for supportive education to reduce their confusion, and psycho-educative programmes have been shown to have some benefit to this end. But partners also need a safe environment, away from their spouse, to discuss their concerns and worries, and consider difficult issues such as separation or divorce. They may benefit from sharing experiences with other partners. Indeed, partners experience the impact of psychosis very differently to parent-carers and therefore need interventions and services to be responsive to this. Partners require forums to consider the changing nature of their relationship to their ill spouse, to consider the impact that the episode is having on their own quality of life, and how their life-goals and future hopes may have to be redefined. How do partners continue to maintain and cultivate social relationships outside of their partnership? And how do they maintain financial viability? Importantly, partners need to pay heed to their own self-care, notably with reference to their personal mental health and physical safety.

Increased societal understanding and acceptance may be a need common to all people who experience mental illness and those who provide support and care. Unsurprisingly, spouses report that social understanding and support from their social networks can be invaluable in helping them through the difficult experiences associated with their partner's illness.

## 7.2 Implications for services

The identified psychosocial needs of partners inevitably have implications for how services respond, and developing an understanding of the needs of service users' families has become central to health care provision. Recent NICE guidance for schizophrenia (2010) includes personal accounts from carers, including spouses, to emphasise this. Additionally by extending support to partners, even though they are not the identified 'service user', services may indirectly contribute to a reduction in psychosocial stressors and to improved mental health and recovery rates for the named client, which even in the current economic climate would make financial sense. Implications of the current review set are discussed below.

Services clearly need to respond to the needs of all carers to be treated in a respectful and sensitive manner. Mannion (1996) suggests that services must establish better working relationships with spouses, and importantly treat spouses *as spouses* and not as carers. There is a significant and qualitative difference between a parent who has (re)assumed a carer's role

and a spouse who defines their relationship in terms of romantic affiliation. For instance, ward staff may require training and education in issues of patient-partner sexuality in order to be sensitive to the needs of couples. Services should also offer supportive counselling to spouses and assist in the consideration of separation or divorce. Additionally, partners may not be married, nor even be cohabitants, with the ill person, which may raise dilemmas and conflicts both legally and relationally with the patient's biological family.

Jungbauer and Angermeyer (2002) suggest that services should offer regular carer-psychiatrist meetings, and that any intervention must be tailored specifically to the couple. They also advocate helping partners to think about divorce and separation where desired.

Services may also need to focus more on offering practical assistance to partners. It is likely that there may be financial implications as a result of the illness, but also a reduction in the collaborative responsibility sharing, such as childcare, household chores, or family responsibilities. Additionally, of course, services will need to be responsive to the psychological needs of partners who are experiencing profound changes to the life they knew. Increased burden, stress, conflict, role changes and social stigmatisation will inevitably impact on the partner and may have serious implications for their own mental health. Laidlaw et al. (2002) suggest that services offer stress reduction groups and coping skills groups for partners, and Jungbauer et al. (2004) discuss the need for spouse-specific intervention groups.

Finally, services need to consider how prejudice is addressed in wider society and how stigma is collectively addressed by all agencies, including government, the NHS, non-governmental organisations (NGOs), charities, schools, faith communities, and citizens and society at large.

### 7.3 Review Conclusions

The aim of the current review was to examine how psychosis affects the spouse or partner of the individual experiencing difficulties. Currently there is a growing research base in this area that is moving away from general mental illness and carers to focus more specifically on psychosis and partners. There are clear differences in how spouses experience the illness of their partner compared to how other family members, notably parents, experience the same phenomena.

Services appear to focus predominantly on parent-carers and may need to ‘catch up’ with the modern phenomena of people experiencing psychosis being in romantic relationships.

A limitation of the current review is that the sub-chapter headings represent somewhat artificially imposed categories. Psychosis has an interactive and complex impact across all domains of people’s life.

#### 7.4 Future Research

As highlighted earlier, the studies in the current review do not draw explicitly on specific theoretical positions. With that in mind it is important to consider how future research may be conducted within, and applied to, particular theoretical frameworks, such as those introduced earlier (see 3.2 Theoretical considerations).

Hopper (2007) revisits the recovery model as applied to psychosis and offers an illuminating view of how Sen’s (1985) Capabilities Approach (CA) can be applied to clinical practice and research in the illness. Originally an approach to welfare economics, CA is now acknowledged as a paradigm in development with regard to human functioning. The approach emphasises functional capabilities (e.g. the ability to participate in political activities) and the emphasis is not only on how human beings actually function, but on their having the capability, which is a practical choice, to function in important ways that they chose. Nussbaum (2000) frames these principles in terms of ten capabilities. In light of the current review the following examples of these capabilities may provide interesting theoretical links to guide future research on spouses of individuals experiencing psychosis: *Bodily integrity*, being able to move from place to place, to be secure against violent assault including domestic violence, and having opportunities for sexual satisfaction and reproduction; *Emotions*, being able to love, grieve, and experience justified anger, and not being constrained through anxiety and fear; and *Practical Reason*, being able to engage in critical reflection and planning of one’s life. Future research might focus on how services can begin to view spouses/partners as individuals in their own right and assist in empowering them make choices about their own lives and to develop their own coping skills, similar to Rychtarik and McGillicuddy’s (2005) work with parents of addicts refusing treatment.

An alternative theoretical framework within which future research might be conducted is Self-determination Theory (SDT). SDT is a macro theory of human motivation and personality,

concerning people's inherent growth tendencies and their innate psychological needs. The theory focuses on the extent to which an individual's behaviour is self-motivated and self-determined (Deci & Ryan, 2002). According to Deci and Ryan (1995) the following three psychological needs motivate the self to initiate behaviour and are essential for psychological health and well-being: *Competence*, being effective in dealing with one's environment; *Relatedness*, the need to interact and be connected to others; and *Autonomy*, the desire to be causal agents in our own life. SDT also distinguishes between intrinsic and extrinsic motivations in relation to the factors guiding human behaviour. Future research conducted within this framework may focus on expanding our knowledge of the choices spouses make (e.g. relating to relationship maintenance or separation, supporting hospitalisation or treatment decisions, developing social contacts, financial decisions, perceptions of quality of life etc), the factors implicated in decision-making, and individuals' intrinsic and extrinsic aspirations.

Other notable areas for development in the literature identified by the current review include further exploration of financial implications of psychosis; understanding the impact of psychosis on partners who are not married or cohabiting; and understanding the factors that lead to enhanced partner resilience. Similarly, the current review focuses on couples who remain in relationships. Future research may focus on the factors associated with separation and divorce and how services can be involved with helping people to resolve difficult life choices.

With the exception of Kumar and Mohanty (2007), the current review set focuses primarily on white, western, heterosexual samples. Much more research is required in addressing the experiences of non-white samples, and people in homosexual relationships.

Finally, the epistemological position adopted is an important consideration in this field of research. As highlighted earlier, the current review focuses on 'impact', which was purposely conceptualised differently to 'meaning'. The above future research suggestions might be more illuminating if conducted through a lens of a search for the meaning of psychosis in one's life. Such future research may be more suited to qualitative, experiential and phenomenological methodologies, such as Smith's (1996) Interpretative Phenomenological Analysis (IPA).

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# **RESEARCH PAPER**

## **THE EXPERIENTIAL IMPACT OF HOSPITALISATION ON FAMILIES OF YOUNG PEOPLE WITH EARLY PSYCHOSIS: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS**

## ABSTRACT

**Objective:** This research examines the experiential impact of hospitalisation on families of young people who are hospitalised with early psychosis. The research aimed to address the following: What is the meaning and impact of psychiatric hospitalisation for the young person's family? What was helpful and / or unhelpful for family members during this time? And, how do family members experience the hospitalisation process, from admission to discharge?

**Method:** Semi-structured interviews were conducted with six participants (parents) and the resulting transcripts were subjected to Interpretative Phenomenological Analysis (IPA).

**Results:** Five phenomenological themes emerged from the data: "Accepting and blaming", "Feeling out of control: 'What shall I do?'" , "Hospitalisation as temporary containment", "Feeling let down by services", and "Stigma". Aspects of the hospitalisation process were characterised as negative for family members, however there are a number of positive affirmations of the containing, supportive and crucial role that hospital, Early Intervention (EI) and voluntary services provide.

**Conclusions:** The current research identifies families' perceptions of hospitalisation as being an understandably difficult, and at times, distressing experience exacerbated by the complexity of being a carer of an adult-child. Negotiating services and boundaries within the context of this relationship can contribute to feelings of exclusion and disregard by professionals and services. The recommendations that would arise from the present findings sit comfortably with the recommendations of current government mental health strategy with regard to how services can face the challenges of engaging and including carers and equipping and enabling them to support their relatives with early psychosis.

**Key words:** *Family caregivers experiences, hospitalisation, early psychosis, early intervention service, Interpretative Phenomenological Analysis*

## 1. INTRODUCTION

It is understood that psychiatric hospitalisation can be distressing, even traumatising (Morrison, Bowe, Larkin, & Nothard, 1999; Meyer, Taiminen, Vuori, Aijala, & Helenius, 1999 ), but little is known about the impact of hospitalisation in the context of services where clients are: a) likely to be hospitalised in a crisis, and probably for the first time, or b) if they are on an Early Intervention Service (EIS) caseload may have the expectation that, because of EI's community-based ways of working, hospitalisation is unlikely.

Whilst psychiatric hospitalisation is understood to be distressing for the individual experiencing the psychotic episode, there are few studies that examine the psychological effects and the phenomenological experience of such admissions. Importantly, even less is known about the impact of hospitalisation on the patient's family, particularly in the context of first episode hospitalisations and therefore this is the focus of the current research.

### Early Intervention Services (EIS) for psychosis

It is estimated that approximately one per cent of the population of the UK will receive a diagnosis of schizophrenia (WHO, 2001). It is widely understood that schizophrenia and psychotic illnesses develop in late adolescence and early adulthood (Harrop & Trower, 2001). EI services have therefore developed within the context of the prevention and management of early psychoses. EI services see young people between the ages of sixteen and thirty-five with a first episode of psychosis, the aim being to provide sustained multi-disciplinary intervention during the 'critical period' of elevated risk of developing the illness. Treatment is aimed at promoting recovery in three areas: symptomatic; social; and psychological. Central to an EI approach therefore is aiming to prevent hospitalisation where possible (Lester, 2004).

### Psychosis and the family

Currently there are few studies that specifically and directly address the impact of hospitalisation on the patient's family per se. A significant number of studies have focused on the dynamic interactions between relatives / caregivers and individuals with schizophrenia. Research themes that are common in this area have focused on experiences of living with schizophrenia (e.g. Saunders & Byrne, 2002), guilt (e.g. Fortune, Smith, & Garvey, 2005), burden (e.g. Lauber, Eichenberger, Luginbuhl, Keller, & Rossler, 2003; Awad & Voruganti,

2008), and caregiver coping (Tennakoon et al., 2000; Martens & Addington 2001). Much of this research has originated from a positivist epistemology, and little is therefore understood from an interpretivist perspective regarding the lived experiences of these participants.

Early qualitative research by Lewis and Zeichner (1960) suggested that families and family functioning were negatively affected by a relative's hospitalisation. This seminal research highlighted the range of experiential reactions to a family member's psychosis including: hostility, fear, confusion, ambivalence, guilt, apprehension, disgust and understanding. Additionally it highlighted a number of carer coping styles such as no change, lowered expectations, change in responsibilities, and self-medicating (alcohol misuse). This research, however, is methodologically limited and situated in the historical and cultural context of 1960's North America; however it represents an early attempt to examine experiential impact.

More recently, a number of studies in the literature have utilised qualitative methodologies to explore the process of a relative developing and living with schizophrenia, and in doing so have indirectly touched upon how family members have experienced the hospitalisation of their relative. An example of this is offered by Barker, Lavender and Morant (2001) who used grounded theory techniques to develop a temporal model of schizophrenia. In their model they identified the following stages: first psychotic episode; events around the time of the first psychotic episode; events around the first hospital admission; and current experiences. Barker et al. (2001) identify the following positive themes for family members following the first admission of their relative: Containment, hope for the future and compassionate professionals. However, the majority of participants reported negative experiences, including not being listened to, having no choices, perceived professional incompetence, feeling blamed and accused, having no coherent explanations, disagreements with professionals, and having poor or limited understandings of schizophrenia. Similarly Ferriter and Huband (2003) examined the experiences of parents with a child hospitalised in a secure forensic setting. The primary aim of this study was to identify the burden experienced by parents and to understand the sources of support viewed as most helpful. Something of the parents' experience can be understood through the themes generated, which were focused heavily around guilt and self-blame. Participants in the study reported that family members and self-help groups were greater sources of support than professional staff. This study provides a contrast to standard in-patient care because of the dynamics relevant to forensic mental health settings. Whilst

such studies offer valuable insights into how family members experience their relative's hospitalisation, they do not directly examine the experiential impact of the hospitalisation *per se*.

Recently, however, Hardcastle, Kennard, Grandison and Fagin (2007) have edited a number of compelling narratives from carers, including parents and partners, regarding their experiences of the hospitalisation of a relative. A number of themes are identified, including the emotional reactions to the illness, reactions to service structures and inpatient conditions, and the general impact that the illness and inpatient process had on the relatives. Commentaries on the narratives are provided by health-care professionals, but these narratives remain unanalysed first-person accounts and therefore their theoretical implication is limited.

Crisanti (2000) offers an important contribution to the literature in this area, examining mothers' experiences of the involuntary hospitalisation of their adult children with schizophrenia. Crisanti's analysis draws on phenomenological techniques, and is idiographic in its use of a small purposeful sample of three mothers. The central theme of the mothers' experience was that of negative encounters with the healthcare system. Five major themes, referred to as common elements, were identified in this study. These included the process being a demeaning experience, feeling baffled by the hospitalisation process, feeling victimised by mental health professionals, and feeling judged as a poor mother. This study represents an important contribution from a qualitative approach and the current research aims to build on this utilising a more robust and theoretical phenomenological analysis and an enhanced sample of family members.

Developing the sample of family members is an important element of the current research. The limited existing literature focuses principally on parents of (adolescent-adult) children who develop psychoses. However, it is understood that the relationship a family member has to the hospitalised individual can alter their experience of the hospitalisation process. For example, Jungbauer, Wittmund, Dietrich and Angermeyer (2004) offer a qualitative exploration, using Grounded Theory, of subjective burden in spouses of schizophrenia patients. They identify similar patterns of guilt, shame, failure, and stigma, and briefly address how enforced hospitalisation can be accompanied by dramatic and shocking incidents involving police and healthcare professionals. The authors also consider the role changes that occur in romantic partnerships that are inherently different to those of a parent-child

relationship, such as relationship conflict and a loss of shared sexuality. Similarly Jungbauer and Angermeyer (2002) conducted a qualitative study of spousal and parental burden. Among their findings their sample identified how caring for a heavily impaired schizophrenic person, as burdensome as it may be, imparted structure and meaning to the spouses' lives. When this structure was disrupted for an extended period through hospitalisation, the spouses reported experiencing a vacuum and loss of meaning.

### The current research

The existing literature indicates that admission to a psychiatric hospital can be a distressing experience for the individual and their family. Currently however, few studies specifically address the experience and impact of hospitalisation from the perspective of the patient's family per se. The current research therefore intends to develop an enhanced understanding of the experiential impact of the process of hospitalisation as understood by the families of young people under the care of EI services.

Understanding the quality of experience of service users and their families has become central to modern health care provision, and recent NICE guidance for schizophrenia (2010) includes personal accounts from carers to emphasise this. More recently, the Coalition Government's strategy document "No Health Without Mental Health" (2011) emphasises the need to support, value and include carers in order to improve recovery outcomes in those with mental ill-health. Consequently, it is anticipated that the current research will not only better inform our understanding of the experiential impact of hospitalisation on the families of young people, but that this understanding will lead to recommendations that may improve the experience of hospitalisation for the so-often forgotten relatives.

### Research question

The primary research question is therefore:

What is the experiential impact of hospitalisation on families of young people, in the context of an early psychosis?

The subsequent questions that the research attempts to address are the following:

- What is the meaning and impact of psychiatric hospitalisation for the young person's family?
- What was helpful and / or unhelpful for family members during this time?
- How do family members experience the hospitalisation process, from admission to discharge?

The current research is concerned primarily with a deep and rigorous understanding of the subjective experiences of those affected by such life events, and in this sense does not seek to elucidate an objective 'truth' about the world. Instead this research is a phenomenological inquiry into the specific experiences of specific people, in specific contexts. As such, a phenomenological epistemological position is adopted.

#### Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) (Smith, 1996) is a contextual-constructivist epistemological approach to data analysis that is informed by phenomenological theory, a branch of philosophy that is concerned with the way humans gain knowledge of the world around them and their experiences.

The founding principle of phenomenological inquiry is that experience should be examined in the way that it occurs, and on its own terms. According to Husserl, it is about understanding the essential qualities of an individual's experience (Smith, Flowers, & Larkin, 2009). As such a positivist approach would not be consistent with what the current research attempts to achieve. Moreover, the philosophers Husserl and Merleau-Ponty were critical of psychology's identification with the natural sciences because they viewed scientific constructs as acting as a screen from experience per se and as offering only second-order knowledge derived from first-order experience (Smith et al., 2009). The current research aims to engage with the first-order experience of the participants, and therefore a phenomenological approach is viewed as necessary.

Smith et al. (2009) suggest that the second major theoretical underpinning of IPA comes from the theory of interpretation: Hermeneutics. Hermeneutics concerns the interpretation of texts. A resonant idea within hermeneutics is 'the hermeneutic circle'. In essence, this asserts that to understand any given part of a text you must look to the whole; to understand the whole, you

must look to the parts; for example a word only becomes clear when viewed in the context of a whole sentence.

It is important to highlight that, within an IPA approach, the analysis produced by the researcher is always and only an *interpretation* of the participant's experience (Willig, 2001). The implications of this are, as Reid, Flowers and Larkin (2005) suggest, that results are not given the status of fact, and the role of the researcher in the analysis should be reflected upon (Elliot, Fischer, & Rennie 1999), particularly because one's interpretation will necessarily be founded upon one's pre-existing conceptions, beliefs, and personal experiences.

The third major theoretical influence on IPA is idiography. Smith et al. (2009) hold the idiographic approach of IPA in contrast to the nomothetic approaches of positivist inquiry. IPA does not seek to make claims about groups or populations, but rather it concerns understanding the experiences of specific people in specific contexts. As such IPA utilises small purposely selected samples. To this end the current research embraces an idiographic approach.

In summary IPA was selected as an appropriate method for the current analysis because it permits greater understanding of the participants' subjective experiences of the hospitalisation of their family member, and allows us to understand something of their first-order experience. Any illumination of experience will not represent an objective reality but rather an interpretation of the reality that is constructed and understood by the participants.

## **2. METHOD**

### Participants

Because of the nature of diagnostic uncertainty in first-episode psychoses the current study does not rely on specific diagnostic categories of young people to limit participant inclusion criteria. Instead participants were family members of patients who were currently under the care of a Midlands Early Intervention Service (EIS), who had been hospitalised with a psychosis in nominated hospitals within the region.

The participant sample used in the current research consisted of four mothers and two fathers. Table 1 displays a participant summary.

Table 1: Participant summary information

<b>Pseudonym</b>	<b>Relative</b>	<b>Relationship to young person</b>	<b>Age of young person (at first hospitalisation)</b>	<b>Carer circumstances</b>
Joan	James	Mother – Son	21 (19)	Employed Part-time / Full Time Carer / Re-Married
Sarah	Chris	Mother – Son	25 (23)	Employed Full-time / Full Time carer / Partner
Claire	Shaun	Mother – Son	22 (20)	Employed Part-time / Limited contact with son until hospitalisation / Now Full Time carer / Live-in-partner
Martin	Ian	Father – Son	18 (16)	Unemployed / Part-time Carer / Divorced
Maggie	George	Mother – Son	20 (18)	Employed Full-time / Full-time carer / Partner
Phillip	William	Father – Son	21 (18)	Retired / Previously Full-time carer, currently Sporadic care / Married

The sample sizes for IPA studies vary but are relatively small because of the approach's idiographic commitment to depth of analysis, and to the reporting of commonalities and differences between individuals' accounts. Recently Smith et al. (2009) have emphasised that the primary concern of IPA is with a detailed account of an individual's experience, and suggest that small sample sizes (between three and six) are often appropriate. Therefore the current sample size of six is held as an appropriate number for the methodology adopted.

The primary inclusion criteria were that the participant's family member had been an inpatient at one of three nominated hospitals; the participant was able to speak to English; they had capacity to consent to the research; and the participant was either living with or engaged in providing care or support for the relative at the time of hospitalisation. If participants met the above criteria, they were considered appropriate for the study; no further exclusion criteria were stipulated.

## Materials

An interview schedule was developed by the researcher in collaboration with the supervisory members of the research team. The schedule, which can be found in Appendix 3, focused on collecting participants' narratives on their experiences of their relatives' hospitalisation.

The interview scheduled was designed in a manner that was consistent with the epistemological underpinnings of an IPA approach. Therefore the overarching research question is directed towards meaning rather than difference or causality. The individual items of the schedule are consequently open-ended and enquire about the participants' understandings, experiences, and sense-making activities, and are specifically situated within the context of their experience of the hospitalisation of their relative. By adopting this approach to questioning, the research is viewed as phenomenological and as being consistent with the principles advocated by Smith et al. (2009).

## Procedure

### Identification and recruitment of Participants

The Midlands EIS acted as facilitative agents in accessing the participant sample. Care co-ordinators were asked to identify potential participants from their caseloads, (a minimum of four months was allocated to ensure sufficient preparatory time). Following this, they approached potential participants to provide them with information sheets and consent forms (for information purposes only at this stage) [see Appendix 4 & 5]. Potential participants were given a minimum of 48 hours to consider taking part. Where participants were willing to be contacted by the researcher, their contact details were made available. The researcher then made contact with the participant to provide further information where required and to arrange the subsequent interview. Signed consent was obtained at the point of interview.

### Interviews

One 90 minute interview was conducted with each participant. Whilst participant's preference, suitability of context and safety informed location selection for individual interviews, each of the interviews was conducted in the participant's home. This arrangement was co-ordinated with participants to ease the burden of their involvement.

Home-based interviews were intuitively appealing from the outset. They eased participant burden, provided them with a familiar and safe environment, increased participant and interviewer flexibility regarding interview times, and meant that there was access to a suitable room for the interview to take place. There were some limitations to home-based interviews; however these were principally isolated idiosyncratic events such as difficulty locating rural addresses, or home-related auditory disturbances such as ringing telephones, visitors and pets, which can have an effect on the quality of sound recordings. Such events proved minor distractions and had no substantive impact on the integrity or quality of the data.

The interview style adopted by the researcher was consistent with Smith et al.'s (2009) principles of IPA interviewing. An interview schedule was used to guide the interview. All interviews were recorded on a digital Dictaphone. Interviews were deliberately slow paced, giving the participant time to reflect and express their experience. The researcher was clear from the outset that the central focus was on the participant and their experience, and it was established that little would be said by the interviewer. A position of naive curiosity was adopted by the interviewer and it was accepted that the interviewee had the experiential expertise. At this point the researcher, as far as is possible, set aside personal pre-existing beliefs and theories, and attempted to enter the participant's experiential world.

### Sequence of Analysis

Firstly, the generated interview data were transcribed according to the principles of IPA suggested by Smith, Jarman and Osborn (1999). The essentials of IPA transcription include constructing a verbatim record of what was said, but non-verbal utterances, length of pauses, and non-verbal social interaction considered irrelevant to a contextual understanding may be omitted. The existing literature for IPA has not prescribed a single method for working with data (Smith et al., 2009) and so the subsequent sequence of analysis drew on recommendations offered by Smith (1996; 2007), Smith et al. (2009) and Willig (2001). Outlined below is the four-stage procedure that was followed:

#### Stage 1: Reading and re-reading

During this stage of the analysis the researcher's primary concern is immersing oneself in the data transcripts. The focus was on "slowing down" and beginning to enter the world of the

participant, responding to what is being read, and entering into a phase of active engagement with the data (Smith et al., 2009).

#### Stage 2: Initial noting

This stage represented the initial level of analysis. Following Smith et al. (2009), exploratory coding began at this stage with a focus on descriptive comments (describing the content that the participant had said), linguistic comments (focusing on the use of language by the participant) and conceptual comments (focused on engaging with the data at a more interrogative and conceptual level).

#### Stage 3: Developing emergent themes

The third stage involves re-organisation of the data and attempts to introduce structure to the analysis (Willig, 2001). During this stage emergent themes are identified, and the researcher takes a more central role in imposing an order (the 'interpretative'), but attempting to remain close to the participant's experience (the 'phenomenological').

#### Stage 4: Searching for connections between emergent themes

The fourth stage involves synthesising the emergent themes into a structured, organised analysis. Both Smith et al. (2009) and Willig (2001) advocate clustering emergent themes in a summary table and looking for patterns across cases. At the end of the process a Master Table is generated displaying how themes are nested within super-ordinate themes. Appendix 6 displays an example extract of the Master Table generated.

#### Credibility

The credibility and trustworthiness of the analysis process and the emergent themes was enhanced by following the recommendations of Banister, Burman, Parker, Taylor and Tindall (1994) and Elliot, Fischer and Rennie (1999) who recommend reflexivity in the research process. As such, a reflective diary was kept throughout the process in order to facilitate reflection on personal assumptions, goals, individual beliefs and subjectivities. A significant point of note is that the current research was one third of a triad of studies exploring the experiential impact of hospitalisation in early psychosis. The three studies focused on the perspectives of young people (patients), their relatives and the hospital staff providing care. In

order to further enhance the credibility and trustworthiness of the analysis and interpretations, emergent themes were discussed in a research team of doctoral students and supervisors. After stages one and two (outlined above) were individually completed the research triad and supervisors met to discuss, review and reflect on process and emergent concepts. This process was repeated following stages three and four. This process of triangulation and validity checking is considered to enhance the credibility of the interpretation and final analysis.

### **3. RESULTS**

From the continual process of intuiting, analysing and describing the accounts of experiences of hospitalisation of parents of young people, five phenomenological themes emerged from the data. The five themes, each with their constituent sub-ordinate themes, were: 1) Accepting and blaming; 2) Feeling out of control: “What shall I do?” 3) Hospitalisation as temporary containment; 4) Feeling let down by services; and 5) Stigma. Each of these themes will be considered below.

#### **1. Accepting and Blaming**

How participants appeared to understand their relatives’ psychotic experience was thought to have a pervasive impression throughout their narratives in terms of the content, language and metaphor used in their accounts. Parents’ attempts to make sense of the illness led them to taking a position towards their relative. These positions appear to be polarised between an ‘accepting’ or ‘blaming’ standpoint. In the accepting position parents understood and did not blame or negatively implicate their relative in the illness onset; they understood the illness to be related to external factors, such as substance use, but justified and normalised this and were able to more easily separate the person from the illness. In the second position the parental standpoint is more negative and blaming. Individuals in this position appeared to view the illness as brought about by the young person who had a responsibility in its development; negativity, blame, disbelief and less sympathetic language characterises this position.

#### **Understanding and non-blaming**

Where participants adopted an understanding and non-blaming position, they appeared more positive toward their relative and separated them from a responsibility in the development of

the illness. They showed a greater tendency to excuse or normalise behaviours considered to be potentially associated with contributing to the development of psychoses such as substance use. The following extract demonstrates how the participant ‘understands’ her relative’s psychosis as an allergy to cannabis:

*“I think all kids experiment with drugs these days, and a lot of them get away with it. Particularly with cannabis, and the strong stuff, some people are allergic to it as you know. And, erm... it... it brings this thing (psychosis) on.”* [Joan, line 108]

Amongst participants who were considered to take an accepting and non-blaming position there appeared a greater capacity to separate the person from the illness. In doing so, parents were able to understand the distressing behaviour of their relative as illness symptomatology and not inherent to them as a person.

*“We realise it’s not Ian, it’s the illness. That’s what I try to tell his mom because she gets really upset... I say “he’s not thinking straight, and when he gets better it’ll go back” which of course it did.”* [Martin, line 436]

### Blaming / Distrustful

In contrast to the first position, a number of participants appeared to adopt a more critical perspective toward their relative. Parents who took this standpoint also shared an understanding of the illness as being related to external factors, such as substance use, but were less likely to justify or normalise drug taking behaviour:

*“I felt ashamed of my son because he was a drug abuser. Nobody likes drugs.”*  
[Claire, line 555]

*“It’s all self inflicted I think. I could be wrong. He has an addictive personality I think.”* [Phillip, line 176]

At the extreme of this position were those parents who actively had difficulty accepting their relative’s experience. The use of dismissive language and doubt in the following quotation is indicative of this and evokes perceptions of malingering.

*“When he was in hospital he was talking about these voices that he was hearing and these images that he was seeing. And I was like, ‘well, where’d you get that from?’*

*This is the first I've heard of it.'... I was just like, you know? Gobsacked and very dismissive of it 'don't be so bloody stupid'". [Claire, line 117]*

In contrast to participants who were able to separate their relative as a person from the illness as a phenomenon, were those participants who came to understand the two as inextricably linked. Below Phillip recalls past events and begins to consider them as early indicators that his son was somehow inherently different or bad.

*"I think it's personality...when he was two, he'd do something wrong and you'd tell him off, you know he'd turn around and give you a look of such pure hatred... And he was an extremely plausible liar even from the age of about three. Normally it's a bit older than that, you can catch them out, but no, not with William, he was perfectly controlled. He worked out how many seconds there were in a day once, in his head, when we were driving back from The Town, when he was eight. You know that's... (shakes head disbelievingly)." [Phillip, line 111]*

In developing a phenomenological understanding of the experiential impact of hospitalisation, the position that participants adopted toward their relative and the illness appears to be a key theme and plays a role in forming their subsequent experiences of the hospitalisation process.

## **2. Feeling out of control: "what shall I do?"**

Participants' narratives indicated that the pre-hospitalisation phase of the illness was experienced as an incredibly distressing and overwhelming time. Whilst these data do not relate specifically to hospitalisation, it is important in understanding participants' subsequent experiences. This phase of the illness was characterised by the nature and extent of their relative's psychosis being revealed. Parents described feeling out of control and at a loss, not knowing how to respond or what to do. In attempts to resolve or reduce these feelings, they enacted proactive strategies to regain some sense of control. Feeling out of control remains a pervasive theme for parents even following their relative's discharge from hospital, where they appear to feel unprepared for the unforeseeable experience to follow.

### **Feeling out of control**

First-episode psychoses are inevitably likely to be characterised by the unprecedented nature of the experience. With no existing knowledge or prior experience to draw on, parents were

left feeling out of control and in crisis. Interviewees commonly described the intense emotional arousal that overwhelmed them and the helplessness they felt. Joan spoke starkly about the moment when she received a telephone call informing her that her son had experienced a psychotic episode whilst on holiday abroad:

*“I was absolutely distraught as you can imagine. Shall I get a flight out there? What shall I do? You know, am I going to help by getting a flight out there? And eventually I thought, no I’m not, I’m not. I’m not going to be able to do anything.”* [Joan, line 97]

This experience was also reflected in Claire’s account of the moment she learned of her son’s hospitalisation:

*“I was in panic mode. I didn’t have anything to do with his father, as such. Who do I ring, who do I contact?”* [Claire, line 26].

Feeling out of control and not knowing how to respond was also a resonant theme for those parents who observed a progressive deterioration of their relative’s mental health. In the following extract Phillip reflects on his son’s limited insight into his ill health and how he and his wife had no control over the developing situation.

*“Well, we just thought there’s something wrong with his mental state and we kept pleading with him to go and see a doctor but he wouldn’t. He kept saying “there’s nothing wrong with me”. The frustration. You don’t know what to do.”* [Phillip, line 43]

### Strategies to regain control

In order to regain some sense of control in overwhelming and unprecedented circumstances, participants engaged in proactive problem solving, often taking the form of practical actions, such as reading material about psychosis. Joan describes how she began making contact with mental health services.

*“I’d kind of planned out in my mind how I was going to deal with it when he got home, and I’d decided that... I’d already called the team, erm, the Early Intervention Team etc, and I’d already arranged for them to come and see him.”* [Joan, line 33]

An extreme example of taking control is offered by Maggie who “*took three months off initially when George was first ill to be at home with him*” [Maggie, line 63]. She develops this further describing how, when her GP did not take sufficient action, she took control.

*“So when the doctor didn’t seem to take it seriously I did take some time off work and I spent the time with George actually, taking him out, I mean he wasn’t getting up in the morning, getting out, showering, he wasn’t looking after himself at all, so I’d make him get up, make him have a shower – well I didn’t make him, I encouraged him! (Laughs). So you know, we’d erm.. we’d go out for walks, and actually that’s when we got our dog”.* [Maggie, line 32]

A natural instinct to make efforts to regain a sense of control over difficult situations can be observed throughout participants’ accounts. However, even following a period of stabilisation in hospital, participants continued to feel unprepared for events to come.

#### Unprepared

*“I so, so wish that I’d had this information before he’d left the hospital.”* [Claire, line 204]

The above extract succinctly captures the unpreparedness that participants experienced upon their relatives’ discharge from hospital. The unpredictability of the unknown, how their relative’s illness might progress, and what the future might hold appears to have left participants feeling a continued lack of control over the situation. The following extract provides a significant insight into a parent’s experience of first-episode psychosis. Claire cries out for predictability and a concrete strategy for facing the coming months, in contrast perhaps to the “open-ended” approach of services who offer diagnostic caution and uncertainty in early onset and first episode psychotic illnesses.

*“It’s about that explanation, you know? It’s about showing and doing. Having a clear cut path over the next six months. What we need to do is have goals... Break it down rather than leaving it open-ended.”* [Claire, line 260]

Claire adds to this the rueful sentiment “*if I had known for one minute when he was discharged from that hospital what he was going to be like, I’d have never have done it (i.e. agreed to provide full time care at home)*” [line 272].

Parents also spoke of feeling inadequately supported, which may also lead to them experiencing an increased sense of not being in control, particularly in a first-episode of psychosis when unfamiliarity and a lack of precedent add to the distressing experience.

*“The lack of support for the carer in the immediate days could definitely be better because it’s totally bewildering. I know for people whose family member may have had a condition for a long time, they’ll be more familiar with everything, but there’s always going to be that stage when it all starts to begin. It might be as a young child, but a lot of them are adults when they begin to experience some sort of psychosis and I do feel that there needs to be more support for the carer when it’s all happening.”*

[Sarah, line 654]

This theme appears to be critical in understanding parents’ experiences of hospitalisation. In the pre-hospitalisation phase parents feel out of control and in crisis. This is likely to inform why they experience the subsequent hospitalisation as containing; however perceptions of being left unprepared at discharge seem to leave parents feeling a continued sense of being out of control, and leave them to reflect on negative perceptions of services.

### **3. Hospitalisation as temporary containment**

Parents’ accounts of the experience of hospitalisation framed it overwhelmingly as an appropriate, proactive event, which ultimately brought them a sense of relief through a number of mechanisms. For parents, their relative was viewed as being physically contained in an appropriate place with access to treatment. In addition the hospital was understood to be a place of safety – both in terms of self-protection and also societal protection. Parents also experienced the hospitalisation, and particular individuals, as providing psychological containment for their distress regarding their relative’s mental ill health. Positive support was also perceived to be provided for the parents post-discharge by agencies external to the hospital per se, including EIS and voluntary agencies. Whilst parents appear to experience the hospitalisation as a proactive and appropriate event, it often leads to them feeling blamed by their relative. Material emerged from parents’ accounts indicating that the young person, perceiving the hospitalisation as a negative event, targeted the parent as the source and cause of their distressing experience in hospital.

## Relief

All of the parents reported a sense of relief following their relative's hospital admission, although their relief was understood to arise through a number of mechanisms.

### *Access to treatment*

Several of the interviewees described access to appropriate treatment as instrumental in bringing about their sense of relief. This is also suggestive of how parents perceived their relatives difficulties as a primarily medical condition. In Joan's narrative she expresses how her son was desperately in need of treatment following his psychotic episode. Her sense of relief is palpable when the doctors agree to a hospitalisation.

*"The doctors said to me "we need to section him". I was relieved. I was absolutely relieved."* [Joan, line 94]

These sentiments are echoed in the following extracts. Both Sarah and Maggie conveyed their understanding that an admission to a psychiatric hospital was viewed as necessary and appropriate, and was ultimately the preferential course of action owing to the severity of nature of the illness and the prospect of treatment and care that a hospitalisation offered.

*"It was the right thing to do. Physically there was nothing wrong with him but mentally he'd had some sort of episode and this was the only way forward, there was no other way forward, there was nothing else for it he had to be taken to the Unit."* [Sarah, line 12]

*"George has got a serious mental health problem and he's in a serious mental health state and that's where he needed to be."* [Maggie, line 118]

### *Safety*

A second mechanism through which feelings of relief were engendered was the safety that a hospital admission provided. In Martin's account he expressed his fear that his son might place himself at risk in the community through his disinhibited behaviour. He conveys how the safety of the hospital contained these anxieties.

*“The Mental Health Hospital is quite secure actually. So I was quite happy that he was there because it felt safe for us really... And that was a big fear because you know, anything could happen to him, you know? When he’s not thinking straight he could say something to the wrong person or people and get hurt!”* [Martin, line 142]

The importance of hospitals as safe places was a prevalent theme throughout participants’ accounts, and even acted as a counterbalance, or compensatory factor, for some of the negative aspects of hospitals, such as their perceived unpleasantness.

*“The building itself is probably quite old, I’m not sure. But definitely wasn’t too nice but it was safe so I was happy about that”* [Martin, line 292]

*“**Interviewer:** Was that very important, that he was safe? **Maggie:** Oh being safe, yea, yea. I mean I don’t like hospitals, I think they’re horrible places to go and stay but it would mean that he would be safe.”* [Maggie, line 111]

As highlighted earlier, the position that participants adopted toward their relative and the illness appears to play a role in forming their subsequent experiences of the hospitalisation process. The following extract captures this concept. Here Claire describes her understanding of her son’s hospitalisation in terms of possible malingering. Whilst she experiences difficulty reconciling the extent of her son’s illness and alludes to him as possibly ‘hiding’ in a psychiatric hospital from the outside world, she derives relief from the notion that the hospital provides safety and security, regardless of her son’s motivations.

*“My understanding was that he was in a lot of trouble in the outside world and tucked away in there it meant that nobody could get at him so I was quite relieved actually.”* [Claire, line 158].

This perspective is also reflected in Phillip’s account. Phillip’s following extracts evoke imagery of prison, particularly in his use of the term “locked up”. He indicated that his son had a history of violence and posed a risk to both himself and society, and in doing so identified the hospital as a place of safety through the very mechanism of physical containment.

*“The first time we went to see him was when he was transferred to The Hospital. There didn’t seem any point in us going, as far as we were concerned he was in the*

*right place. He was locked up in a place where he couldn't do any harm to himself or other people. Because he did have a history of violence, he had a couple of convictions for violence as well.*” [Phillip, line 67]

*“It was the right place for him to be. Couldn't think of anywhere better for him to be. He obviously needed to be erm... (pause) he couldn't be allowed out in society because of what he might do.”* [Phillip, line 113]

### *Relief of burden*

A number of participants identified the hospitalisation as providing a relief of the burden of caring. In Martin's account he expresses how stressful caring for a young person with psychosis can be and how the hospitalisation provided a sense of respite.

*“[It was] The best place for us as well you know, because he's such really hard work when he's out when he's ill so it gave us a bit of time as well to bloody de-stress sort of thing.”* [Martin, line 219]

Claire also expresses the difficulties associated with caring for a young person with psychosis in her account and how this is exacerbated by the competing demands of everyday life. Her son's hospitalisation provides her with some relief; however the expressive language used clearly highlights her position in relation to the illness.

*“It was a relief when he went in to hospital because I just couldn't cope with it. Trying to deal with him, trying to run a business, trying to deal with my husband, trying to deal with my family as well. I was like “get a grip I can't do this” so actually they did do me a favour, they did me a big favour – get him in there, that's one monkey off my back and I can go and visit him in hospital.”* [Claire, line 327]

### Feeling contained

Bion's theory of containment (1959) describes the process of helping a person contain their own anxieties and emotions so that they do not feel overwhelmed by these feelings and have increased capacity to think about a situation. This concept can be identified throughout a number of participants' accounts. In the following extracts, Sarah describes how talking with a psychiatrist, despite him providing limited feedback, was experienced positively:

*“Being able to talk to the psychiatrist was really good, I don’t know if he was on call, or if he’d come over from the clinic probably. That was helpful, really helpful. And he didn’t have all the answers.” [Sarah, line 207]*

*“We just found a little room somewhere and he came over and saw me because he was coming over to the Clinic anyway and he came and saw me and just chatted to me and I thought that was really nice... he just came over and had a chat and that was really helpful, that was nice that somebody had taken the time out to come and talk to me about Chris” [Sarah, line 469]*

### *Supported*

Whilst parents were often critical of hospitals and perceived them as insufficiently preparing them for their relative’s discharge, several of the accounts described how positive support was provided post-discharge by agencies external to the hospital, including EIS and voluntary agencies.

*“Yea, the Early Intervention side of it – very good, very, Yea, they’ve always been there for me.” [Joan, line 330]*

*“I’ve had a lot of support through the Early Intervention Team, and I had support from Jan through some caring organisation [Rethink]. She came out and did a lot of family work with us” [Claire, line 495]*

During Maggie’s account she identified how she experienced support provided by the EIS worker, and how both she and her son developed a strong relationship with her.

*“You know because like, you know Helen, she’s been lovely, an absolute rock, for both myself and George. We’re very lucky to have met her. She’s just, well, she’s such a lovely person that goes without saying. It isn’t just me that likes her, it’s George as well, he’s got a lot of respect for her because you know she’s just been 100% behind us, you know she’s just very, very supportive.” [Maggie, line 304]*

### Feeling Blamed by the young person

Whilst parents appear to experience the hospitalisation as a proactive and appropriate event, it was frequently accompanied by the distress of feeling blamed by their relative. Inevitably, for

young people involuntarily hospitalised, the event was experienced from a fundamentally different perspective to their parents. Throughout interviewees' accounts material emerged indicating that the young person blamed the parent as the source and cause of their distressing hospital experience.

*“He had this great hatred of me, whatever it was, so it was very difficult for me, it was a great hate. And I think it stemmed from I was the one, I actually put him into the hospital.”* [Joan, line 164]

In addition, parents also discussed feeling blamed for the development and onset of the illness itself:

*“He sort of blamed us really, well mainly his mom, because he said ‘you should have seen the signs earlier and told me’ but we did tell him, and his mom pointed that out and said ‘we did tell you Ian but you wouldn’t listen to us, you wouldn’t take your medication’. And like he’d say ‘you could have done it earlier and got me on the medication and it wouldn’t have got this bad’”* [Martin, line 429]

This theme is further elucidated by Martin, who describes how he attempts to reconcile feeling blamed with his view that he is acting in his son's best interests:

*“I mean obviously if you go and section someone they’re not gonna like it, and sort of blame us. And he did blame us, definitely. But you just have to take it, I suppose, just got to do it haven’t you, that’s what we thought, obviously we do it just to try and do the best for him really, not us.”* [Martin, line 252]

Parents' narratives indicated that hospitalisation was initially experienced as an appropriate proactive event that delivered a sense of containment. Notably, however, this sense of containment appears to offer temporary respite that succumbs to feelings of blame and negative experiences of services as illustrated further below.

#### **4. Feeling let down by services**

This was the most starkly recorded aspect of parents' experiences of the hospitalisation process. A pervasive theme throughout parents' accounts was that they felt let down by inadequate service provision. Predominantly this aspect of interviewees' narratives was

characterised by negative perceptions of services, which led them to feel disregarded as a parent. Parents appeared to feel disregarded through not being provided with coherent explanations, being excluded from the process, and not being listened to and valued. In addition parents perceived services and professionals as lacking in competence, and being bewildering and overwhelming.

### Disregarded as a parent

A principal theme generated in all participants' accounts was feeling disregarded as a parent. This experience was engendered through a number of exclusionary practices employed by services. Chief amongst these was that hospitals were limited in the information they could provide to parents of adult children because of confidentiality regulations. Almost all of the parents interviewed experienced this as distressing.

*“Interviewer: what was that like at first when you couldn't get information? Martin: Well, not very good obviously, you know, you phone up to ask how's your son and they can't give you any information at all. They were very limited they'd say “he's just the same, he's the same as he was” you know what I mean? So they wouldn't give hardly anything... I don't think it's on really, is it?” [Martin, line 245]*

Parents' accounts also indicated that they perceived the hospitals to exclude them through the lack of coherent explanations they offered, particularly regarding diagnosis and treatments.

*“What would have been nice would have been for someone to sit us down and explain what was wrong with him, you know what I mean? Because they didn't really say anything about anything. What medication he was taking, or anything really, we didn't get any information, what sort of side effects, what does it do, how does it work, you know? We didn't get anything.” [Martin, line 343]*

This lack of clarity is also reflected in parents' perceptions of the poor communication they experienced from hospital staff.

*“It was always “he's very poorly, he's been very poorly”. “Yeah, well I was poorly when I had a hysterectomy, what does that mean!? What, he's got stomach ache or something? I don't know! What's 'poorly'?” It was jargon, a different language. If they thought they were communicating to me they weren't.” [Claire, line 292]*

This exclusionary disregard ultimately led parents to feeling not valued as either a carer or parent, as Sarah describes:

*“It’s difficult because he’s an adult, there were certain things that he didn’t want me to be privy to and yet I’m essentially his carer and I’m his mother, and I know him better than anybody and I feel I should have been consulted more”* [Sarah, line 622]

Furthermore, Claire conveys her sense of being disregarded through staff members not valuing her point of view and treating it dismissively.

*“They heard what I was saying, they didn’t listen to what I was saying. There are two different, two totally different versions. You can hear something or you can listen to something.”* [Claire, line 444]

In addition to staff interaction, parents also explained how they found the Mental Health system disempowering and frustrating.

*“When he starts talking gibberish we now recognise that he’s leading up to it. And we call the Crisis Team or whatever they’re called and they’d come out and talk to him “oh, he’s perfectly alright (laughs)”. It’s a nightmare, a nightmare. But that’s the system isn’t it. Apparently there needs to be a doctor, two doctors and a trained, mentally health trained Social Worker and they all have to have a formal meeting and agree. Even if one doctor from what I can gather has seen what is obviously psychotic behaviour, if in the formal meeting he comes across as being normal they can’t take any action. Which I find, well, it makes me very frustrated, very frustrated, very angry.”* [Phillip, line 307]

### Lack of professional competence

Parents’ negative experiences appear to be further compounded by their perceptions of a lack of professional competence from the staff members and service provision they encountered. Interviewees’ accounts described a pattern of perceived lack of professional competence throughout the entire hospitalisation process. This experience was acknowledged as beginning during the early stages of psychosis. In the following extract Maggie acknowledges how her GP did not recognise her son’s symptoms of psychosis:

*“I did take him to the doctors then, but the doctor didn’t seem to, he just told him to eat fruit and stop smoking, and cut down on his alcohol.”* [Maggie, line 24]

A lack of professional competence was also experienced during the process of enacting the Mental Health Act at the point of the initial hospitalisation.

*“The Social Worker as well was absolute rubbish. She just didn’t know what she was doing... She was such an idiot, unbelievable. Really did our heads in. Just, at a very stressful time, just incapable of doing her job.”* [Martin, line 492]

Phillip adds to this, suggesting that weekend admissions are characterised by a lack of staffing and poor organisational practices.

*“He didn’t get seen by a doctor until... it might have been the Tuesday I’m not sure. Erm... so that didn’t seem too well organised. If you’ve got to go into a mental hospital don’t go in at a weekend! Because there’s no staff there, which there should be, or there should be, especially when there are people coming in.”* [Phillip, line 126]

Further to this, Phillip questions the treatment approaches used whilst his son remains an inpatient:

*“Actually they are letting him out for jogging apparently – (wry look, sigh) they know what they’re doing... (pause) apparently.”* [Phillip, line 432]

And finally, upon discharge parents perceived services to continue to not provide adequate support.

*“The Early Intervention Team did say they were going to step it up and have family meetings and explain all this and explain all that, but nothing. His mom said she would do it and obviously I would as well but it never happened. They said they were going to see Ian a lot more but that’s not happened either. It’s really frustrating at the least. If they say they’re gonna do something they should do it. And why haven’t they done it, I don’t know, I can’t say obviously.”* [Martin, line 443]

### Bewildering and overwhelming

Throughout participants' narratives a recurrent negative that was raised was the confusing and bewildering nature of services. Parents' difficulty navigating this complex system is likely to be exacerbated by it being their first experience of hospitalisation. A key theme was that services overwhelm relatives with too many people and too little explanation.

*“when I was at the hospital talking to the intervention team, you’ve got all these people coming at you. “Who are you then?” “There’s my number” “But what do you do?” Doctors... It’s like, so who do I actually speak to about this... do I ring you? Having so many people is very unhelpful.” [Claire, line 194]*

*“There’s so many different parts, sections, and we haven’t really got a clue what’s what, who’s who?” [Phillip, line 365]*

Parents also described certain practices as being experienced as overwhelming, such as multi-professional meetings to which parents are invited. Martin describes his son’s appeal hearing as overwhelming:

*“he actually did a bloody appeal to get out, so that was stressful as well. There was like about six people in the room. I came out with a blinding headache!” [Martin, line 130]*

In addition, Claire describes how specific practices that are intended to make services more accessible can themselves create intimidating atmospheres. In the following extract she describes how a staff photograph board had the opposite effect of that intended:

*“I think you know, also where it was situated in reception by the office area where they all sat, I felt a bit like looking in, I was a bit embarrassed, I did, I just felt a bit embarrassed, everyone looking at me. So you know, I’d actually put that just before you come into the ward, or both places, so the patients have got it, obviously you have to think of the patients, but also for people coming into the ward can actually stand and study either on their way in or out of the ward without feeling a bit intimidated. They’re not trying to intimidate you but that’s just the feeling you get.” [Claire, line 361]*

Parents' overwhelming experience of hospitalisation is that of a distressing and bewildering process where they are left feeling disregarded and peripheral to their relative's care. Initial perceptions of being contained appear to subside as parents feel increasingly excluded by services.

## **5. Stigma**

Material surfaced from participants' accounts that elucidated their perceptions of the stigmatising nature of mental illness. Parents perceived Mental Health services and hospitalisation to be stigmatising but also suggested that society at large was notable for its negative attitudes toward mental illness.

### Services as stigmatising

The nature and practices of services were experienced by parents as being associated with stigma and embarrassment. Below, Joan describes the moment that the ambulance indiscreetly came to transport her son to hospital and in the confusion evoked curiosity and concern from neighbours:

*“when the ambulance came they were wandering around the village because they couldn't find us where we were, and I actually ran out after them, and I did find that quite (pause) you know (pause), it just happens to be this area you know with the house names. And then obviously someone came out and said “oh Joan, what's the matter?” You know, and I just kind of ignored it and carried on.”* [Joan, line 115]

Some parents were also able to reflect on the impact of diagnostic classification and the imposed meaning that engendered, and the labels that young people risk being attributed.

*“I don't want any diagnosis because diagnosis labels people for the rest of their lives and I didn't want anything else because you can say with a psychosis, ok you know, it's just a temporary thing isn't it? It can be? Whereas when you put a label on someone, you know they're stuck with that thing and I didn't want that.”* [Maggie, line 219]

### Society as stigmatising

A number of accounts alluded to the lack of societal understanding of mental illness and the negative perceptions that are commonplace in the community.

*“But mental health – people say there is a taboo over it, and there is really, because people they don’t understand it.” [Joan, line 176]*

*“what I find is a lot of people don’t understand they think “oh he’s just lazy, or there’s something wrong with Chris, why isn’t he doing this or that”. I find that hard” [Sarah, 260]*

It was notable that parents described how their concern was greater for their child than themselves.

*“obviously there was the embarrassment of a mental illness and then for him to go back to college after it, if he’d have been acting weird that’s what I was worried about and going back to work as well. **Interviewer:** You were worried for him? **Martin:** Oh, yea, not for me, I’m not embarrassed about it at all. But for Ian himself, because I know he feels that way” [Martin, line 455]*

And finally, Phillip ruefully reflected how he felt society judges and blames the parents of young people with mental ill health:

*“I don’t know what else we could have done... We tried so hard. But it’s always the parent’s fault isn’t it!” [Phillip, line 95]*

Evidently stigma continues to be a notable and distressing theme experienced not only by those who live with mental ill health but also the relatives and carers who support them. Ostensibly, services themselves have some way to go to eradicating stigmatising elements from their practice.

#### 4. DISCUSSION

The current research set out to explore the experiential impact of hospitalisation on families of young people, in the context of early psychosis. Aspects of the process were characterised as a negative experience for family members, however it is important not to underestimate the relief and containment that hospitalisation can provide during this time.

It was not the aim of the current research to discover ‘new facts’ regarding families’ experiences of hospitalisation; rather the intention was give voice to an unheard, idiographic, purposeful sample, with a view to informing understandings of their experiences and considering how these narratives might inform service provision. Of note is that the current analysis should not be considered to reflect all family members’ experiences or represent truisms regarding the phenomena of hospitalisation. Specific reflection should be offered concerning my own position in relation to the analysis, particularly as a fundamental component of IPA is the interpretation of data. Therefore any phenomenological analysis produced by the researcher is always, and only, an *interpretation* of the participant’s experience (Willig, 2001). Notably, my training and experiences in clinical psychology, particularly working within inpatient psychosis services, have afforded me the opportunity to witness first-hand the organisational and service pressures placed upon hospital staff and structures. Balancing my understanding of how infinite demand placed upon finite resource contributes to family members’ dissatisfaction with a desire to do justice to participants’ narratives and give voice to their distress was challenging. My unique role as both a researcher external to the service under study, but also as an NHS employee within a separate inpatient service, located me in a complex position in relation to this research. Methodological strategies (outlined in the Method) which were designed to enhance the credibility of the analysis and interpretations were critical to maintaining perspective in the interpretation.

Through their narratives, parents described their position in relation to their relative and the illness. In addition, parents described feeling out of control and in crisis during the pre-hospitalisation phase of the illness and welcomed the hospitalisation as a proactive and appropriate course of action. By taking control and offering professional expertise, services were able to contain parents’ distress, albeit temporarily. Predominantly, parents reported feeling excluded and disregarded by mental health services, and inadequately prepared for their relative’s discharge, which returned them to feeling out of control and in distress.

Parents were also able to reflect both on how some practices of mental health services and societal perceptions of mental illness remain stigmatising for young people and their families.

### **Key areas of interest**

Perhaps understandably, parents spoke in depth about feeling out of control and in crisis during the pre-hospitalisation phase of the illness. This finding is not highlighted in the existing literature, and is likely to reflect the unique experience of family members witnessing their relative's first episode psychosis. A lack of precedent is likely to exacerbate feelings of distress and lack of control, which go some way to explaining why hospitalisation was so welcomed by parents. In contrast to existing literature, themes of guilt, self-blame (Ferriter & Huband, 2003), shame and failure (Jungbauer et al., 2004) were absent in the accounts of current participants. Instead, parents viewed the hospitalisation as a proactive, appropriate strategy, and believed themselves to be acting in their relatives' best interests. In accordance with Barker et al. (2001) parents described feeling grateful to services for the containment offered through admission. This might be understood in terms of a return to control that the parents experienced through ensuring their relative was safe and had access to appropriate treatment. Regrettably for parents, their experience of containment proved to be temporary and participants described subsequent negative experiences of hospitalisation.

Negative experiences identified in the current research were congruent with findings in the existing literature. Feeling disregarded as a parent was common to all accounts in the current study and this feeling was engendered through a number of experiences, including not being provided with coherent explanations, being excluded from the process, and not being listened to and valued; similar themes are identified by Barker et al. (2001) who, amongst other themes, reported 'not being listened to' and 'having no coherent explanations' as criticisms raised by parents. The experience of services as 'bewildering and overwhelming' echoes the findings of Crisanti (2000), who noted that parents felt baffled by the hospitalisation process. In addition, a number of participants in the current study referred to the stigmatising potential of psychosis and psychiatric hospitalisations; this is in-keeping with the considerable literature in this area (see Phelan, Bromet, & Link, 1998). Of note, was that this was not a dominant theme within participants' narratives and, where present, it was largely raised in the context of parents' fears that their child would experience stigmatisation, as opposed to the

“associative stigma” (Mehta & Farina, 1988; Goffman, 1963) that they themselves might experience by virtue of their association with the individual with psychosis.

An intriguing finding was the position adopted by parents in relation to their relative and their illness. Seemingly, parents’ attributions of responsibility in the development of the illness influenced their experiences of the hospitalisation process and their understanding of illness symptomatology. This finding is notable as it is congruent with Lewis and Zeichner’s (1960) early qualitative work, and is resonant of the expressed emotion (EE) concept. EE is a construct based on attitudes of caregivers toward the patient. Relatives are classified as high in EE if they make more than a specified number of critical comments or show signs of hostility or emotional over-involvement (Bruckner *et al.*, 2008).

Further exploration of the Family Systems and Expressed Emotion literature may aid an enhanced understanding of the current findings. Family Systems theories suggest that individuals cannot be understood in isolation but rather as part of an interconnected and interdependent family system. Cox and Paley (1997) discuss the literature in this area and highlight how the influence of systemic thinking can be seen in work of early family therapists (e.g. Ackerman’s psychoanalytic approach; Bowen’s multigenerational transmission of pathology; the Bateson group’s family communication patterns research; Haley and the Palo Alto group’s development of strategic family therapy; the Milan group’s systemic family therapy, and Minuchin’s structural approach, emphasising family organization and regulation of boundaries). Family system theories have been highly influential in the study of psychiatric disturbance given the focus on inter and intra-personal transactions. However, Milkowitz (2004) discusses how the theory’s credibility as a working model has been limited by its historical assumption that psychiatric disorders (such as psychosis) are caused by disturbed family environments, and that modifying these disturbances is essential to alleviate distress. Milkowitz highlights how this conceptualisation neglects genetic, biological, and non-familial risk and protective factors. Current thinking in this area indicates that family environments play an essential role as *moderators* of the course of psychiatric illness.

Closely associated with this is the notion that EE levels are an important moderating factor in psychiatric disturbance. Psychotic patients who live with, or are in association with, high-EE relatives are at least twice as likely to relapse within twelve months post-hospital discharge

(Butzlaff & Hooley, 1998). In Milkowitz's (2004) review of the literature on Family Systems and EE he suggests that there are at least four explanations for variability of EE levels in families: a) EE is a reaction to symptomatology amongst patients; b) EE is a product of psychopathology within the relative(s); c) EE is associated with the relatives' attributions about the patient's behaviour; and d) EE is a function of reciprocally dependent family interactions.

Aspects of the current research findings could be read as idiographic examples of elevated levels of EE in family systems. Milkowitz (2004) cites Hooley and Gotlib (2000) who suggest that relatives become critical or hostile when they make internal, personal, or controllable attributions about the causes of negative patient-related behaviours, particularly behaviours that disrupt family functioning, involve socially undesirable behaviour, or involve rejection of help. Such attributions are evident in the narratives of Claire and Phillip within the theme of "Blaming / Distrustful". Hooley and Gotlib (2000) further suggest that low-EE relatives, in contrast, are more likely to attribute negative behaviours or events to external, universal, or uncontrollable factors, including the effects of an illness. Again, these attributions are evident in the narratives of Joan and Martin within the "Understanding and non-blaming" theme. We might speculate that participants who attribute negative patient behaviours to external, universal, or uncontrollable factors might derive some comfort from doing so. It is also possible that preferences for a biomedical view of psychosis (an illness that was visited upon the young person) may even have the benefit of moderating and maintaining low-EE levels, but Milkowitz (2004) cautions that a purely biomedical view of psychosis may not reduce relatives' fears or resentments. Indeed, such attributions may ultimately lead to feelings of helplessness and hopelessness and a lack of control.

Family intervention (FI) for psychosis has sought to address identified difficulties and reduce distress within family systems. To this end, FI has a robust evidence-base indicating its efficacy, and findings consistently indicate that adding FI to medication can reduce relapse rates to one-third of their expected rates (Milkowitz, 2004), similar findings are reported in a recent Cochrane Review meta-analysis (Pharoah, Mari, Rathbone & Wong, 2010). The two principal modes of delivery for FI are multiple-family and single-family intervention. Evidence indicates that the two variants of intervention have comparable efficacy, however are likely to achieve outcomes through different mechanisms of change. Whilst the

mechanisms of change in FI are not fully understood (Kuipers, 2006), Milkowitz (2004) suggests that single-family formats may operate by enhancing family communication, affective expression, conflict reduction, strengthening alliances and boundaries, improving hierarchical organisation, and by increasing the patient's commitment to medication regimes. In contrast, multiple-family formats may operate by reducing the impact of stigma, improving problem-solving, increasing social support, and increasing family knowledge of the mental health system.

It was notable that participants' accounts in this project indicated the need to address family communication, affective expression, conflict reduction, the impact of stigma, social support and families' ability to negotiate the mental health system. Evidently, the imperative is on identifying appropriate family intervention formats on a need-determined basis for each family. Fadden (2009) asserts that, in terms of timeliness, offering help as early as possible is recommended; families are particularly willing to engage in times of crisis such as during acute episodes or during hospital admissions (Fadden, 1998; Hardcastle et al., 2007).

### **Implications for practice**

Whilst the current findings may prove uncomfortable reading for those associated with mental health service provision and hospitalisation per se, embedded within parents' narratives are numerous opportunities and challenges to address. Importantly, there are a number of positive affirmations of the supportive and crucial role that hospital, EIS, and voluntary personnel and services provide and it is the responsibility of services to seek to build upon these.

The current Coalition Government's mental health outcomes strategy, *No health without mental health* (2011), offers a relevant strategic framework for seeking to address a number of challenges identified by the current research and the current findings would appear to evidence the strategy's statement:

*“Families and carers, young and old, often receive limited help and too often report that they are ignored by health professionals on grounds that they need to protect the confidentiality, and respect the wishes, of the service user. However, families and carers, including children, have detailed knowledge and insight and are often best placed to advise health and social care professionals about what may help or hinder the recovery of the person for whom they are caring. If they are well supported and*

*listened to, families and carers can continue their caring responsibilities for longer and participate fully in decisions about services and how care is delivered.” [No health without mental health, 2011 p.33]*

The current 2011 strategy document cites *The Triangle of Care – Carers included: A guide to best practice in acute mental health care*, which sets out six key elements of good practice for mental health professionals working with carers. Amongst these, the current research would indicate that the following key elements are particularly relevant: “*Staff are ‘carer aware’ and trained in carer engagement strategies*”; “*Policy and practice protocols on confidentiality and sharing information are in place*”; and “*A range of carer support services is available*”.

The current research would specifically highlight the importance of training hospital staff in carer engagement, with a particular focus on the containing influence they can have during the initial stages of the admission and also with regard to inclusion, communication and information sharing. Similarly, the current research findings would highlight the importance of developing practice protocols on confidentiality and information sharing with patients’ relatives and would advocate contracting with involved individuals regarding how and what will be disclosed. Developing individualised contracts would reduce carers’ feelings of disregard and exclusion by services, and lay out clearly defined respectful boundaries, and increase flexibility in information sharing when dealing with the parents of an adult-child. The carer’s need for information must be balanced with the service user’s right to privacy (Szmukler & Bloch, 1997) and when consent is withheld professionals face an ethical dilemma between non-malificence (i.e. not doing harm through failing to disclose) and beneficence (i.e. doing good by respecting the patient’s wishes). Slade et al. (2007) propose a framework for best clinical practice, which makes an important distinction between “general information”, which can always be shared without consent, and “personal information”, which is new to the carer and where consent needs to be considered. In their framework, Slade et al. present a decisional-based model regarding what information to share, where the central mediating factor is clinical judgement. In addition, they suggest two levels of action, “organisational” (i.e. service level protocols) and “clinical” (i.e. professional responsibility of clinicians), which should both be considered in decision taking. The current research would advocate the need to introduce such frameworks as commonplace in psychiatric hospitals.

Finally, the current research findings would support the need for identified staff members as a point of contact and source of information in order to reduce feelings of overwhelming and intimidating services, and encourage reciprocity and dialogue between services and family members. Whilst services, such as EIS, are available to family members, nominated hospital service supports available to carers and families would facilitate smoother transitions between admission and discharge and reduce feelings of being overwhelmed and out of control.

### **Summary**

In summary, the current research identified families' perceptions of hospitalisation as being an understandably difficult, and at times, distressing experience exacerbated by the complexity of being a carer of an adult-child. Negotiating services and boundaries within the context of this relationship contributes to feelings of exclusion and disregard by professionals and services. The recommendations that would arise from the present findings sit comfortably with the recommendations of current government mental health strategy with regard to how services can face the challenges of engaging and including carers, and equipping and enabling them to support their relatives with early psychosis.

### **Looking ahead**

The present study utilises a small and purposeful sample consistent with IPA guidelines. However some sampling limitations should be noted. This study sought to utilise an enhanced sample of family members in order to further the existing literature. To some extent this was achieved with the inclusion of fathers, both living with and separated from the young person's mother. Evidently there is a notable absence of siblings and spouses in the current sample. This is thought to reflect the limited number of sibling and spouse carers that have been identified in previous research (e.g. Jungbauer & Angermeyer, 2002). Moreover, the current sample consists only of parents of hospitalised males; potentially the experience of parents of hospitalised females may generate alternative narratives. Furthermore, whilst the sample accessed is thought to represent the local demographic, the composition is limited by the lack of Black and Minority Ethnic participants. In addition, it should be noted that it is possible that participants who volunteered for the current study may have been motivated by their powerful stories and experiences, which is likely to have introduced a bias to the analysis. Little is known about those who declined to participate in the study.

Constraints in access to service users and carers (e.g. carer-forums) prior to the research meant that the method, including design of the interview schedule, was constructed without input from young people or their relatives. Future exploration of the phenomena under investigation may be strengthened by carer involvement from the outset. Similarly, a further limitation is that practical constraints meant that transcripts and collected and analysed data were not fed-back to participants. Sample validation of this type is not standard practice in IPA research (for reasons outlined in Smith, Flowers, Larkin, 2009), though it can help to make findings persuasive to a wider audience.

As outlined in the Method, the current research was one third of a triad of studies exploring the experiential impact of hospitalisation in early psychosis. Whilst supervisory practices, validity checking and triangulation methods were utilised in attempts to enhance the credibility of the analysis and interpretations (see Method), it should be considered that these practices may have influenced the interpretative process. Being familiar with the content of carer, patient and staff narratives may have further implicated researcher subjectivity and introduced additional layers of bias to the interpretations and structure of the analysis.

Looking ahead, research may choose a number of avenues to explore. In the phenomenological tradition research may address sampling limitations identified above through further targeted recruitment, or indeed, actively seek to illuminate factors associated with positive hospital experiences. Conversely, positivist approaches may be used to investigate comparisons between experiences of first hospital admissions and subsequent admissions, perhaps facilitated by EIS, and what impact EIS can have on parents' psychosocial conceptualisations of psychosis, and how this may affect EE levels. As the current government Mental Health strategy develops, there will be a need for service level research regarding minimum standards for provision for carers in this domain, who provides this, and how outcomes are monitored.

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## **PUBLIC DOMAIN BRIEFING PAPER**

### **The experiential impact of hospitalisation on families of young people with early psychosis: an Interpretative Phenomenological Analysis**

This paper describes a qualitative study conducted by Gareth Hickman and presented as part of a thesis for submission to the School of Psychology, University of Birmingham for the Doctorate in Clinical Psychology.

#### **Background and Aims of the Research**

It is understood that psychiatric hospitalisation can be distressing, even traumatising (Morrison, Bowe, Larkin, & Nothard, 1999), but little is known about the impact of hospitalisation in the context of services where clients are: a) likely to be hospitalised in a crisis, and probably for the first time, or b) if they are on an Early Intervention (EI) Service caseload may have the expectation that, because of EI's community-based ways of working, hospitalisation is unlikely. Notably, even less is known about the impact of such hospitalisation on the patient's family, particularly in the context of first episode hospitalisations.

It is widely understood that psychotic illnesses develop in late adolescence and early adulthood and therefore EI services typically see young people between the ages of sixteen and thirty-five with a first episode of psychosis.

Past studies of family members' experiences of living with a person with psychosis have indicated that it can be a distressing and disruptive illness. Periods of hospitalisation have been associated with some positive experiences such as containment, hope for the future and compassionate professionals. However, the majority of research participants report negative experiences, including not being listened to, having no choices, perceived professional incompetence, feeling blamed and accused, having no coherent explanations, disagreements with professionals, and having poor or limited understandings of the illness (e.g. Barker, Lavender & Morant, 2001). Crisanti (2000) offers a brief but important contribution in this area, examining mothers' experiences of the hospitalisation of their adult children with schizophrenia. Mothers identified the process as being a demeaning experience, feeling

baffled by the hospitalisation process, feeling victimised by mental health professionals, and feeling judged as a poor mother.

This research aimed to develop an enhanced understanding of the experiential impact of the process of hospitalisation as understood by the families of young people under the care of EI services, exploring the meaning and impact of psychiatric hospitalisation, what was helpful and / or unhelpful, and how family members experience the hospitalisation process, from admission to discharge.

## **Method**

The research participants were six family members (four mothers and two fathers) of patients who were under the care of EIS, who had been hospitalised with an early onset psychosis. Family members were interviewed in depth about their experiences of their relatives' hospitalisation, from admission, during the hospitalisation, and through to discharge. The interviews were semi-structured and an interview schedule was used to guide the process. The individual items of the schedule were open-ended and enquired about the participants' understandings, experiences, and sense-making regarding the hospitalisation. The interviews were transcribed and then analysed using the Interpretative Phenomenological Analysis technique (IPA; Smith, Flowers, & Larkin, 2009; Willig 2001). IPA was selected as an appropriate method for the analysis because it permits greater understanding of the participants' subjective first-order experiences and allows us to understand something of the sense they made of the hospitalisation process.

## **Findings**

Five phenomenological themes emerged from the data:

### 1) Accepting and blaming

This theme constituted two sub-themes: 'understanding and non-blaming' and 'blaming / distrustful'. These themes related to parents' attempts to make sense of the illness and the positions that they adopted in relation to their relative. In the accepting position parents

understood and did not blame or negatively implicate their relative in the illness onset; In the second position individuals appeared to view the illness as brought about by the young person who had a responsibility in its development.

#### 2) Feeling out of control: “What shall I do?”

This theme constituted three sub-themes: ‘feeling out of control’, ‘strategies to regain control’, and ‘unprepared’. When discussing the pre-hospitalisation phase of the illness, parents described feeling out of control and at a loss, not knowing how to respond or what to do. In attempts to resolve or reduce these feelings they employed proactive strategies to regain some sense of control. Feeling out of control remained a pervasive theme for parents even following their relative’s discharge from hospital, where they continued to feel unprepared for the unforeseeable experience to follow.

#### 3) Hospitalisation as temporary containment

This theme constituted three sub-themes: ‘relief’, ‘feeling contained’, and ‘feeling blamed by the young person’. Parents’ accounts of the experience of hospitalisation framed it overwhelmingly as an appropriate proactive event, which brought them a sense of relief through a number of mechanisms (e.g. access to treatment, safety). Parents also experienced the hospitalisation as providing psychological containment for their distress regarding their relative’s mental ill health. Positive support was also perceived to be provided for the parents post-discharge by agencies external to the hospital, including EIS and voluntary agencies. Parents also spoke of feeling blamed by their relative as the source and cause of their distressing experience in hospital because they supported the admission.

#### 4) Feeling let down by services

This theme constituted three sub-themes: ‘disregarded as a parent’, ‘lack of professional competence’, and ‘bewildering and overwhelming’. Predominantly this aspect of interviewees’ experiences was characterised by negative perceptions of services, which led them to feel disregarded as a parent. Parents appeared to feel disregarded through not being provided with coherent explanations, being excluded from the process, and not being listened to and valued. In addition parents perceived services and professionals as lacking in competence, and being bewildering, confusing and overwhelming.

## 5) Stigma

This theme constituted two sub-themes: ‘services as stigmatising’ and ‘society as stigmatising’. Parents perceived aspects of Mental Health services and hospitalisation to be stigmatising but also suggested that society at large was notable for its negative attitudes toward mental illness.

### **Discussion and Conclusions**

The current research identified families’ perceptions of hospitalisation as being an understandably difficult, and at times, distressing experience exacerbated by the complexity of being a carer of an adult-child. Negotiating services and boundaries within the context of this relationship contributes to feelings of exclusion and disregard by professionals and services. The recommendations that arise from the present findings sit comfortably with the recommendations of current government mental health strategy with regard to how services can face the challenges of engaging and including carers and equipping and enabling them to support their relatives with early psychosis. Importantly, there are a number of positive affirmations of the containing, supportive and crucial role that hospital, EIS, and voluntary personnel and services provide and it is the responsibility of services to seek to build upon these.

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# Appendix 1

## OVERVIEW OF DESIGN, SAMPLE, AND ANALYSIS OF REVIEWED ARTICLES

<b>Table 1: Quantitative Studies</b>									
<b>Author, Year &amp; Country</b>	<b>Sample</b>	<b>Control Group</b>	<b>Comparison Group</b>	<b>Method of Data Collection</b>	<b>Method of Data Analysis</b>	<b>Theoretical Perspective</b>	<b>Area of Impact Assessed</b>	<b>Quality Issues</b>	<b>Transferability</b>
Angermeyer et al. (2006) (Germany)	N =133 F:44% R, D A, O	Quasi Randomised	Depression Anxiety	Self-administered questionnaires	Multiple Regression	None Given	Quality of Life	S Rep Ra	Low response rates German sample only
Angermeyer & Bull et al. (2006) (Germany)	N=261 (133 partners) F:45.9% R, D, A,	No	Nurses	Self-administered questionnaires	Multiple Regression	None Given	Caregiver Burnout	S Rep Ra	Low response rates German Sample No data on non-respondents
Bruckner et al. (2008) (Germany)	N=80 F:50%	No	Published studies on EE	Interview	Mann-Whitney U T-Test	None Given	Expressed Emotion	S Rep Ra	Includes data from healthy happy partners
Croake & Kelly (2002) (USA)	N=136 F:50% R, A, E,	No	Bipolar	Questionnaire	ANOVA	Adlerian	Marital Adjustment	S F Rep Ra	Focus on married couples
Crowe (2004) (UK)	Review	No	No	Review	Not specified	None Given	Impact of mental illness on spouses	Ra	Limited review of selected topics
Kumar & Mohanty (2007) (India)	N=70 F:50% R, A, O	No	No	Interviewer administered assessment measures	T-Test	Psychodynamic	Burden	S Rep Ra	Focus on Indian socio-demographic Impacts/culture

Laidlaw et al. (2002) (UK)	N=85 (32% partners) A, D	No	Living Together Living Apart	Interviewer administered assessment measures	T-Test	None Given	Caregiver stress	S Rep Ra	Focus on living situations and relatives as well as partners
Wittmund et al. (2002) (Germany)	N=151 F:44.4% R, D, A, O	No	Anxiety Depression General population	Structured interview / administered measures	Logistic Regression	None Given	Depression in partners	S Rep Ra	Data compared to general population of Germany
Manion et al. (1994) (USA)	N=19 F:74% E, O, D,	No	Family focused intervention	Questionnaires	Pearson correlations	Psychoeducation	Psychoeducation for spouses	Rep Ra F	Limited sample, no RCT or control
Phelan et al. (1998) (USA)	N=156 (14% spouses) F:81% A, R,	No	Other family members (Non-spouse)	Telephone Interview	T-Test Chi Square	None Given	Stigma	S Rep Ra F	Focus on different SES groups

<b>Table 2: Qualitative Studies</b>									
<b>Author, Year &amp; Country</b>	<b>Sample</b>	<b>Method of Data collection</b>	<b>Method of Data Analysis</b>	<b>Theoretical Perspective</b>	<b>Epistemological Position</b>	<b>Area of Impact Assessed</b>	<b>Reflexivity</b>	<b>Quality Issues</b>	<b>Transferability</b>
Hardcastle et al. (2007) (UK)	N=1	Personal Narrative	None	None Given	None Given	Impact of hospitalisation	None	Sy GE Ra	Unanalysed Individual account Ad
Jungbauer & Angermeyer (2002) (Germany)	N=103 F:32% (52 partners) A, O, R,	Individual narrative interviews	Thematic Field Analysis Grounded Theory	None Given	Interpretive	Burden	None	GE C Ra Rep	Compares partners and family members responses Ad
Jungbauer et al. (2004) (Germany)	N=52 F:46% A, O, R,	Individual narrative interviews	Grounded Theory	None Given	Narrative	Burden	Research as process	GE C Ra	Ad

	D,							Rep	
Manion (1996) (USA)	N=18 F:67% A, R,	Survey	None	None Given	None Given	Resilience and burden	None	Sy GE C Ra	Ad

Key

Sample	Quality Issues	Qualitative Only
<p>F: = Female</p> <p>E = Ethnicity data provided</p> <p>R = Description of Relationship given (Married, engaged, cohabiting, apart)</p> <p>D = Duration of relationships provided</p> <p>A = Ages of sample provided</p> <p>O = Data provided re onset of illness prior to or during relationship</p>	<p>S = Standardised outcome measures used</p> <p>F = 6+ month follow-up</p> <p>Rep = Method allows for replication</p> <p>Ra = Sound rationale provided</p>	<p>Sy = Does not appear to be a systematic analysis of data</p> <p>Ad = Transferability issues not explicitly addressed</p> <p>GE = Grounded in examples</p> <p>C = Coherence</p>

## Appendix 2

### INSTRUCTIONS TO AUTHORS FOR REVIEW PAPER

## CLINICAL PSYCHOLOGY REVIEW

Available at:

[www.elsevier.com/wps/find/journaldescription.cws\\_home/652/authorinstructions](http://www.elsevier.com/wps/find/journaldescription.cws_home/652/authorinstructions)

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# Appendix 3

## INTERVIEW SCHEDULE

### Introduction Question

Can you tell me a little about the kinds of Mental Health difficulties that your family member has experienced / been experiencing?

### Section 1.

Can you tell me the story of how your family member came to be hospitalised?

*Follow up questions:*

(What was going on for you and your family at the time?)

How were you and your family involved in the hospitalisation process?

Did you feel your views and opinions were listened to during the hospitalisation process?

What, if anything, did you find helpful during this time?

What, if anything, did you find unhelpful during this time?

(Can you tell me about the length of time this process took?)

### Section 2.

Can you tell me what it was like for you during the time that your family member was in hospital?

Can you tell me what it was like for your family during the time your family member was in hospital?

Can you tell me what it was like for your family member during the time that they were in hospital?

*Follow up questions:*

Did you receive sufficient information about: the illness / the hospitalisation process / the hospital / treatment / families rights / families responsibilities / access / discharge planning?

What information, if any, would you like to have received that you did not?

What did you think of the hospital environment? Appropriateness / other patients?

Do you feel that your family member received the appropriate treatment during their hospitalisation?

What was your relationship with the hospital staff like?

How were access and visits to your family member organised? Distance / flexibility / visiting rooms?

What, if anything, did you find helpful during this time?

What, if anything, did you find unhelpful during this time?

### Section 3.

Can you tell me about your family member's discharge from hospital?

*Follow up questions:*

How long was your family member hospitalised for?

How was the discharge planning process arranged?

What was your involvement in the discharge planning process?

Did you feel your views and opinions were listened to during the discharge phase?

Where was your family member discharged to?

To what extent were you supported through the discharge process? By Whom?

How did you feel about your family member's discharge from hospital?

What were your concerns / worries / fears / hopes about your family member's discharge from hospital?

### Closing Question

If you were to offer a piece of advice to services on how they could improve the hospitalisation process for others, what would that be?

# Appendix 4

## PARTICIPANT INFORMATION SHEET

**Title of Project:** The experience of hospitalisation in early psychosis

**Researcher:** Gareth Hickman, University of Birmingham

The current research project is being undertaken as part of a doctorate in Clinical Psychology at the University of Birmingham.

This study will involve interviewing family members (such as parents, partners, or siblings) of young people who have been hospitalised due to their psychosis, whilst under the care of the Early Intervention Services (EIS). Early Intervention Services aim to keep people out of hospital, and to enable recovery by other means. We know that psychiatric hospitalisation can be distressing for the person who is hospitalised, but little is known about the impact of the hospitalisation on the wider family. Furthermore, little is known about the impact of hospitalisation in the context of services where young people are often hospitalised in a crisis, and probably for the first time, and may have thought that this was unlikely to happen.

The aim of this research is therefore to spend some time asking family members about their experiences in order to establish what the impact of the hospitalisation was on the family, what they found helpful and / or unhelpful, and to learn more about how family members experienced the hospitalisation process.

- **What is the purpose of this research?**

The purpose of this research is to establish:

- 1) What is the impact of psychiatric hospitalisation on the young person's Family?
- 2) What was helpful and / or unhelpful for family members during this time?
- 3) How do family members experience the hospitalisation process?

- **Why have I been invited to take part?**

You have been invited to take part in this research because you have been identified as a family member of a young person who has been hospitalised whilst under the care of the Early Intervention Service.

- **What will happen to me if I agree to take part?**

All that you will be asked of you is that you give approximately 90 minutes of your time to talk to a researcher about your experience. Your participation will be anonymous and your identity will not be stored with your comments. Your responses will be given a code number and the list containing this number with your name will be kept safely and then destroyed once all the data have been analysed. Some of your responses ‘word-for-word’ will be put into a written report but anything that you say will remain anonymous.

- **What will happen if I do not want to carry on with the study?**

Your participation in this research is completely voluntary. You are free to withdraw from the research study at any stage without giving a reason. Following your interview you will have up to one month to withdraw your consent for your interview data to be analysed.

- **Expenses and payments**

Your participation in this research is voluntary.

Although there are no direct benefits for participants it is hoped that there will be a value to discussing your experiences. It is also hoped that the outcome of the research will help to develop better services for people experiencing an early psychosis and their families.

- **What will happen to the results of the research study?**

On completion of the research study the responses gathered from all participants will be analysed and written up for publication. Please indicate on the consent form if you would like an accessible copy of the research findings upon completion.

- **What happens if I have any further concerns?**

This information sheet is yours to keep, if you have any further concerns please contact any member of the research team (all details below). Alternatively you can contact your associated care co-ordinator at the Early Intervention Service. You will also have access to the EIS at all times to discuss any issues that arise following the interview.



## Appendix 6

### EXAMPLE EXTRACT OF THE MASTER TABLE OF THEMES

Theme	Extract	P'pant / Line
<b>Master Theme 1 Synopsis</b>	<b>Tries to capture something of the position that parents take towards the young person following the sense they make of the illness. Appears to be polarised between an accepting position where parents understand and do not blame; they understand the illness to be related to external factors (e.g. drug use) but justify and normalise this and can separate the person from the illness. The second position taken is more negative and blaming. They see the illness as brought on by the young person; they have a responsibility in its development. Negative, blaming, disbelieving and unsympathetic language is used in the second position.</b>	
<u><b>Master Theme 1: Accepting and Blaming</b></u>  Understanding & non-blaming	<p>“he was taking quite a few sorts of vitamins, which had probably reacted with the medications he was taking, which were natural products – powders and things, you know like what they have in South America and... nothing, no hard drugs or anything, they never found any hard drugs in his system and he told me he'd never taken any hard drugs, so I've never had any qualms about that.”</p>	2/87
Blaming / distrustful	<p>“we realise it's not Ian, it's the illness. That's what I try to tell his mom because she gets really upset. She says “well people with these illnesses they tend to speak the truth from what they're thinking. I say “he's not thinking straight, and when he gets better it'll go back” which of course it did.”</p>	4/436
	<p>“when he was in hospital he was talking about these voices that he was hearing and these images that he was seeing. And I was like, “well, where'd you get that from? This is the first I've heard of it.”... I was just like, you know? Gobsmacked and very dismissive of it “don't be so bloody stupid”</p>	3/117
	<p>“It's all self inflicted I think, I could be wrong. He has an addictive personality I think.”</p>	6/176

## Appendix 7

### **INSTRUCTIONS TO AUTHORS FOR RESEARCH PAPER**

Journal Details: Psychosis

Instructions for Authors

Available at:

[www.tandf.co.uk/journals/authors/rpsyauth.asp](http://www.tandf.co.uk/journals/authors/rpsyauth.asp)

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