

# **Fathers' experiences of caring for an adult child with psychosis: A qualitative study**

Submitted to the University of Hertfordshire in partial fulfilment  
of the requirements of the degree of Doctor of Clinical  
Psychology

Bina Sharma

June 2018

Word count: 31,394

(Excluding tables, references and appendices)

## **ACKNOWLEDGEMENTS**

I would to thank everyone who helped me carry out this research. My biggest thanks goes to the fathers who agreed to take part. I am so grateful to them for sharing their experiences with me so openly and honestly.

To my supervisors, Saskia and Nicola, thank you for your time, advice and expertise over this research process - it has been invaluable to me. To my peer supervision group, I am glad that I shared this journey with you.

To my family and friends - main shabdon mein kabhee nahin kai sakati ki main aapakee kitanee saraahana karati hoon.

## CONTENTS

<b>CHAPTER 1: ABSTRACT</b>	<b>5</b>
<b>CHAPTER 2: INTRODUCTION</b>	<b>6</b>
2.1 General Introduction	6
2.2 Use of Language	7
2.3 Definition of Key Terms	7
2.3.1. What is meant by the term 'carer'?	7
2.3.2. What is meant by the term 'psychosis'?	7
2.4 My Relationship to the Topic	9
2.5 Epistemological Position	10
2.6 Prevalence and current context	11
2.6.1 Psychosis	11
2.6.2 Carers	12
2.6.3 Carers for people with psychosis	12
2.7 Recognition of carers in UK policy	14
2.8 Psychological models	17
2.8.1 Cognitive model of caregiving in psychosis	17
2.8.2 Psychological Therapies	20
2.9 Systematic Literature Review	21
2.9.1 Literature Search Strategy	22
2.9.2 Overview of Findings from Systematic Literature Review	23
2.9.3 Experiences of caring	24
2.9.4 Experiences of mental health services	32
2.9.5 Experiences of hospitalisation	34
2.9.6 Synthesis of Findings	36
2.9.7 Summary of systematic literature review	37
2.10 Research Question	39
<b>CHAPTER 3: METHOD</b>	<b>40</b>
3.1 A qualitative approach	40
3.2 Consideration of other methodologies	40
3.3 Interpretative Phenomenological Analysis	42
3.3.1 Phenomenology	43
3.3.2 Hermeneutics	43
3.3.3 Idiography	44
3.3.4 Strengths of IPA	44
3.3.5 Weaknesses of IPA	45
3.4 Participants	46
3.4.1 Recruitment	46
3.4.2 Inclusion and Exclusion criteria	48
3.4.3 The Sample	48
3.5 Ethical Considerations	50
3.5.1 Informed consent	50
3.5.2 Confidentiality	50
3.5.3 Potential distress	51
3.6 Carer Consultation	51
3.7 Data Collection	52
3.7.1 Interview schedule	52

3.7.2 Pilot Interview	53
3.7.3 Procedure	54
3.8 Data Analysis	55
3.8.1 Individual case analysis	55
3.8.2 Cross-case analysis	56
3.9 Quality of Qualitative Research	57
3.9.1 Sensitivity to context	57
3.9.2 Commitment and rigour	58
3.9.3 Coherence and transparency	59
3.9.4 Impact and importance	60
<b>CHAPTER FOUR: RESULTS</b>	<b>61</b>
4.1 Father vs. carer	64
4.1.1 I'm a father first	64
4.1.2 As a father, you would do anything for your child	65
4.1.3 Being a parent can hinder caring role	68
4.2 Change in quality of relationship with child	70
4.2.1 For better or worse	70
4.2.2 Protecting child vs. looking after self	74
4.2.3 Spending quality time with <u>all</u> your children	77
4.3 To share or not to share	81
4.3.1 Sharing eases isolation	81
4.3.2 Sharing is risky	84
4.4 Acceptance is a struggle	86
4.4.1 A double-edged sword: Feeling helpless	87
4.4.2 Trying to make sense of why and how this happened	88
4.4.3 Hope vs. Loss	91
4.5 Mental health services: inconsistency vs. luck	94
4.5.1 When services get it right, it can be life-changing	94
4.5.2 Services supporting child support parents	97
4.5.3 We need to advocate for our child	99
<b>CHAPTER FIVE: DISCUSSION</b>	<b>102</b>
5.1 Overview	102
5.2 Return to the research question	102
5.3 Summary of Results	102
5.4 The tensions in being a paternal carer	102
5.5 The enduring nature of caring	106
5.6 Relationship between services and paternal carers	107
5.7 Clinical implications	108
5.7.1 Service-level implications	108
5.7.2 Community-level implications	110
5.7.3 Family-level implications	110
5.7.4 Individual-level implications	112
5.8 Methodological considerations	113
5.10.1 Strengths	113
5.10.2 Limitations	114
5.10.3 Quality Assurance	115
5.9 Suggestions for further research	116
5.10 Personal reflections	117

5.11 Conclusion	120
<b>6. REFERENCES</b>	<b>121</b>
<b>7. APPENDICES</b>	<b>134</b>
Appendix 1: Flow Chart of Literature Search Process	
Appendix 2: Summary & Evaluation of Studies in Literature Review	
Appendix 3: Quality of the Research utilised in Literature Review	
Appendix 4: Ethics approval from	
Appendix 5: Amended Ethics approval form	
Appendix 6: Recruitment Summary Email	
Appendix 7: Participant Information Sheet and Consent Form	
Appendix 8: Non-disclosure, confidentiality agreement for transcription	
Appendix 9: Debrief Sheet	
Appendix 10: Interview Schedule	
Appendix 11: Transcript from interview with Leo	
Appendix 12: Example of clustering themes for Leo	
Appendix 13: Superordinate and subordinate themes for individual participants	
Appendix 14: Cross-referencing of themes across the data set	
Appendix 15: Quality Assurance for current study	
Appendix 16: Reflective diary extracts	
Appendix 17: Additional theme added 'In it together'	

### List of Tables

Table 1: Literature Search Terms
Table 2: Literature Search Inclusion and Exclusion Criteria
Table 3: Participant Demographic Information
Table 4: Superordinate and subordinate themes of IPA account

## CHAPTER 1. ABSTRACT

### **Aim**

Previous research has looked at parental experiences of caring, which has highlighted the rewarding nature of caring but also the difficulties associated with this role. However, within these studies the majority of parents have been mothers, meaning little is known about fathers' experiences. Therefore, the aim of this study was to explore how fathers describe and make sense of their experiences of caring for an adult child with psychosis.

### **Method**

A purposive sampling method was used to recruit fathers from local carer groups and forums. Semi-structured, in-depth interviews were carried out to capture information about paternal experiences of caregiving. Research questions encompassed 'What sense fathers had made of their child's psychosis?', 'How their child's psychosis affected their relationship with them over time?', and 'How being a father affected their caring role?' Interviews were transcribed and analysed using interpretative phenomenological analysis (IPA; Smith, Flowers & Larkin, 2009). Seven participants were interviewed including six biological fathers and one step-father.

### **Results**

Five superordinate themes emerged: 'Father vs. carer', 'Change in quality of the relationship with child', 'To share or not to share, 'Acceptance is a struggle', and 'Mental health services: inconsistency vs. luck'. These consisted of fourteen subordinate themes. The themes illustrated that participants did not see being a carer as a separate role, but part of being a parent. They were just as invested and involved in supporting their child as the mothers, and were willing to go any lengths to do this, even if at a personal emotional and physical cost to themselves.

### **Conclusions**

It is important that services reconsider their perceptions of fathers, how they involve them and offer interventions to them (both individual therapy and family therapy). General Practitioners can be more actively involved in checking in with fathers, signposting them to support and resources.

## CHAPTER 2. INTRODUCTION

### 2.1 General Introduction

This research aims to explore fathers' experiences of caring for an adult child with psychosis using IPA. In this introductory chapter, I will define key terms that will be used throughout this thesis, as well as present my relationship to the topic and epistemological position. I will then provide a systematic overview of the relevant and current literature to this topic. Following a synthesis of the evidence-base, this chapter will conclude with the rationale for the present study. As a way to illustrate my self-reflections throughout this thesis process, these will be presented at different points (to highlight this, these reflections will be italicised and underlined).

### 2.2 Use of Language

This doctoral thesis is written in the first person, which fits with and reflects my epistemological stance. I acknowledge that my own views and experiences have influenced this project and I hope that by writing in the first person will allow me to provide my reflections throughout this thesis.

The term 'psychosis' or 'psychosis-related difficulty' will be used throughout, unless referring to literature which has used different terminology. This may include terms such as 'mental health problem', 'mental ill health', 'mentally ill', 'severe mental illness (SMI)', 'first-episode psychosis (FEP)', 'psychological distress', 'psychological disorder' and 'diagnoses'. At points, the term 'illness' will be used to remain consistent with participants' who used this term in their descriptions.

*Personally, I found it difficult using terms such as 'schizophrenia' as this form of 'labelling' does not fit with my position on how I conceptualise psychosis or how I talk about this with service users and their families. However, I am aware of the*

issues around diagnoses, how these are used by professionals and researchers and how it may shape results and recommendations. I held these in mind whilst carrying out this research and discussed this with my colleagues and supervisors.

The term 'child' or 'children' refers to adults that are over the age of 18 years, that have experienced psychosis. Whilst recognising that these terms may not accurately reflect the ages of the children of the participants, it is congruent with how they referred to the sons and daughters they care for. As such, it felt important for this project to continuously remember the relationship context, particularly in latter parts of the thesis. Again, different terminology may be used in relation to the literature which may include 'service user', 'relative' and 'offspring'.

The term 'father' includes biological fathers and father-figures, such as step-fathers. It felt important to make this term as inclusive as feasibly possible, to capture the full breadth of father-carer experiences, within the constraints of the project and methodology. The terms 'paternal carer', 'parent' and 'carer' will also be used interchangeably, particularly in the results and discussion sections of this thesis.

## **2.3 Definition of Key Terms**

### **2.3.1. What is meant by the term 'carer'?**

Carers in general are defined as "anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support" (Carer's Trust ([n.d.]).

### **2.3.2. What is meant by the term 'psychosis'?**

Psychosis is a very broad term used to describe a range of conditions affecting the mind, which can interfere with how a person thinks, feels and behaves. Commonly, there seems to be a loss of connection with reality; individuals may

experience hallucinations (for example, hearing voices, seeing images, smelling or tasting what others do not), unusual or strong beliefs about events, people and situations (for example, belief of being persecuted by a secret organisation) and difficulties in organising their thoughts, expressing themselves in a clear fashion and engaging in everyday living (Division of Clinical Psychology, 2014).

Some clarity is needed with regards to the historical research and literature, which often uses the term 'schizophrenia' or 'schizophrenia-spectrum disorders'. The former refers to one of the diagnostic categories that lie within psychosis. Therefore, in the current study, the term 'schizophrenia' has been used only when referring to the research studies that have also used this term. In all other sections of this thesis, the term 'psychosis' or 'psychosis-related difficulty' has been used, as it highlights the breadth of experiences that that the term psychosis encompasses in the literature. It also widens the focus, attempting to be more inclusive and pay less attention to diagnostic criteria. I also hope that using this term will make this research more relatable and accessible for potential participants and readers, as well as being in line with my epistemological position.

Early on in the research process (mirroring my clinical experience), I noticed the potential areas of conflict in focussing on adults with psychosis and their carers. This was around caring for an adult child who has adult rights, compared to caring for a child and the parental rights and responsibilities that come with this. Throughout this research process, it was useful for me to keep this in mind and I feel that it would be useful for you as the reader to also do so. I have considered the tension this conflict creates in the caring role at various points during the thesis.

## 2.4 My Relationship to the Topic

Upon embarking on this research, it is important for me to reflect on and for the reader to be aware of my stance as the researcher, particularly in the context of the chosen methodology. My interest in carer-related issues stems from my own experience of being a carer for a short period of time for one of my parents with a physical health problem. This not only afforded me increased insight into the impact of physical health problems on one's mental health, but also highlighted to me the importance of involving families and carers in a person's care and potential recovery. Understandably, the treatment was focussed on targeting the physical health problem; nonetheless, I found myself feeling frustrated at times that there was not a space for me and my family to talk through our concerns, as well as the impact and implications of the physical health problem on us.

Prior to embarking on Clinical Psychology training, I worked in a specialist psychological interventions service for psychosis, with Family Intervention (FI) being one of the therapies offered to clients and their families. Whenever possible, the service included families and carers in individual therapy and worked towards increasing awareness of the importance of the needs and outcomes of carers for people with psychosis. From assessing carers before and after therapy, using measures of wellbeing and carer-related outcomes, I was able to learn first-hand the impact that psychosis and its related distress had on the people around the person experiencing it. I was also surprised by the numbers of carers who said it was the first time they had been asked about their own wellbeing, and how much they valued the experience. For me, this brought to light how often mental health services and professionals neglect the wellbeing and needs of carers and family members of people with psychosis, despite there being policies and guidelines around this (these

are outlined later on in this chapter). This led me to choose this area for the thesis, where I would perhaps have the opportunity to enable carers to directly share their experiences.

*Since embarking on this thesis, I have been working in an Early Intervention in Psychosis (EIP) service for my final year specialist placement. I have noticed similar issues to those described above. Even though this has made me more passionate about this research, I felt more responsibility in doing a 'good job' on behalf of my participants as if I am advocating for them in some way.*

## **2.5 Epistemological Position**

“Phenomenology is a philosophical approach to the study of experience” (Smith et al, 2009, p.11). The key aspect of phenomenology is thinking about what the “experience of being human is *like*” (p.11), specifically in how one has come to understand their experiences of the world, which may be influenced by their context (Gergen, 2009).

The phenomenological approach provides a rich source of ideas in how lived experiences can be analysed, understood and appreciated. This is explained in more detail in the Method (section 3.3.1). Therefore, in line with this, I was keen to develop a research study that acknowledged individuals' experiences and sense of meaning-making. I acknowledge that my own experiences, beliefs and meaning-making processes have influenced this project and may have had some impact on the process of analysis.

## **2.6 Prevalence and current context**

### **2.6.1 Psychosis.**

Psychosis can affect anyone and approximately 2% of the general population will experience an episode of psychosis during their lifetime (Kuipers, Onwumere & Bebbington, 2010). There are significantly higher rates for black and ethnic minority groups (BME; Kirkbride et al., 2012), thought to be as a result of selective migration, misdiagnosis based on racist assumptions, traumatic experiences, unemployment and social adversity. This translates to about one in 200 people having a psychotic disorder (given that the over-16 population in the UK is about 49 million), suggesting around 245, 000 people will be affected. Recent figures suggest that over 21 million people worldwide will be living with a diagnosis of schizophrenia (World Health Organisation, 2018). Psychosis is unlikely to be attributed to any one single cause; research is on-going but currently shows that the causes are complex and likely due to several issues that include genetics and biochemistry, psychological and social factors. The exact influence of any of these factors will vary from one person to another (World Health Organisation, 2018).

Research evidence suggests that service users who are supported by carers, achieve better outcomes, including fewer inpatient admissions and relapses, better engagement with services and treatments, and improved life expectancy (Onwumere et al., 2016). Therefore, family members providing care is important for the recovery of people with psychosis and, in turn, can reduce the burden experienced by the family (Ewertzon et al., 2010).

### **2.6.2 Carers.**

The 2011 census suggested there was about 5.8 million unpaid carers in the UK, with 58% being female and 42% male; the highest burden of care falls on the

50-64 age group for both sexes (Carers UK, 2015a). This is a rise of around 600,000 (11.5%) from the 2001 census statistics (White, 2013). There has also been a rise in the number of carers dedicating 50 or more hours a week to looking after family and friends, with the figure currently standing at 1.36 million - an increase of 300,000 over the last 10 years (Carers UK, 2015b). Carers UK's (2015b) annual survey (of over 5,000 UK carers) showed that 84% of carers feel more stressed, 78% feel more anxious and 55% reported that they were affected by depression due to their caring role. This was an increase from the 2014 findings, where 82% had increased stress, 73% reported anxiety and 50% were suffering from depression.

Of the above figure for unpaid carers (5.8 million), around 25% (1.5 million) care for someone with mental ill health (Office for National Statistics, 2013).

### **2.6.3 Carers for people with psychosis.**

In the UK, given that approximately 245,000 people suffer from a psychotic disorder and half of these people will have caregivers, at any one time around 120,000 people will be taking a primary caregiver role (Kuipers et al., 2010). Of this figure, 36% are parents and 65% are female (Roick et al., 2007). Carers for people with psychosis spend an average of six to nine hours a day providing care (Magliano et al., 1998). This informal care, coupled with not being able to work or reducing working hours, saves the public approximately £1.24 billion a year in health care costs (Schizophrenia Commission, 2012).

Historically, caring has been seen as a negative experience with the word 'burden' commonly used to describe the experience (Magliano et al., 1998: 2005; Gutiérrez-Maldonado et al., 2005; Roick et al., 2007). It is unclear if this concept has been ascribed by professionals and the wider society or comes from carers

themselves; indeed carers may see their caring role as a duty or responsibility rather than burden and this concept will be considered further later (see section 2.9.3).

Carers have reported that caregiving can be mutually rewarding and a strongly positive experience, with a sense of increased personal development and feeling that they are becoming a more understanding person (Chen and Greenberg, 2004). They also report feeling a greater bond with the person they care for, as well as satisfaction from seeing them content and appreciative of their care (McCann et al., 2015). However, caregivers of people with psychosis have the additional difficulties of dealing with the stigma, shame and social isolation associated with a psychosis-related diagnosis. Furthermore, they have to deal with confusing and distressing illness symptoms from the person they care for, such as persecutory delusions and/or voices, poor self-care, and risky health behaviours. This may also include aggressive or self-harming behaviours, which can be further stigmatising for carers (Kuipers et al., 2010). There are also the added difficulties of having to navigate the mental health system; deal with numerous clinical staff; and understand diagnosis, prognosis, medication, sectioning and treatment. This is particularly overwhelming in first episode psychosis (FEP); relatives report difficulties understanding psychiatric terminology and gaining recognition and support from healthcare services (Kingston et al., 2015). Given this, perhaps it is understandable they have described struggling to understand the lived experience of their loved one with psychosis, putting a strain on the family relationships (Wainwright et al., 2015).

As a result, carers of people with psychosis often experience high levels of stress, exhaustion and distress with approximately 40% of carers reporting poor psychological functioning (Onwumere et al., 2016). There is evidence that being a caregiver has an impact on their own physical health, as they experience higher

rates of sleeplessness, social isolation, feelings of loss, grief and anger, and report poor satisfaction with health and social care services. Being a carer can have financial implications as family members may need to reduce working hours or give up work completely in order to care for the person with psychosis (Yesufu-Udechuku et al. 2015). In addition, caregivers report posttraumatic stress symptoms (PTSS) related to their caring role, which may have implications for their caregiving experiences and coping efforts (Kingston et al., 2015). Therefore, caring for a person with psychosis is complex, often undervalued and insufficiently supported by services (Roick et al., 2007). This emphasises the importance of understanding caregivers' experiences, assessing carers' needs and offering needs-led therapeutic interventions (Kingston et al., 2015).

## **2.7 Recognition of carers in UK policy**

It is useful to outline the carer-related policies and frameworks for the reader, so that they have some understanding of the political and socio-economic context of this research area from the outset. The key points are summarised below:

### **Care Act 2014 (updated in 2016).**

The regulations under this new Care Act (The Care Act, 2016) place an onus on services to recognise carers in the same ways as those they care for. Part of this is to recognise the role and importance of carers, and to give them more statutory rights to support themselves and the person they care for. Their key rights under the updated Care Act 2014 are for carers to be offered or able to request a Carer's Assessment, to claim Carers Allowance or receive a personal budget as part of their support plan, and to receive services in their own right.

**Mental Health Act 1983 (amended by 2007 Act).**

The amendments to the Mental Health Act (1983) focused on carers being better supported and more involved in planning, however, this is dependent on whether the carer is the nearest relative. Their key rights under this act are briefly summarised here:

- to be included on the Care Plan for person they care for and to be given a copy of this plan (with service user's consent or if issues of duty of care or risk override their objections)
- to be given general information about the condition of the person they care for (though not specific information if the service user does not consent)

If the carer is the nearest relative, they have the right:

- to request a Mental Health Act assessment for the person they care for
- to be informed of the service user's detention and when they are due to be discharged from hospital (unless they or the person they care for has stated that this information should not be divulged)
- to have the person they care for discharged from hospital (giving 72 hours' notice), however, the doctor in charge of their care can prevent this action
- to express their point of view when the service user's detention is reviewed by tribunal or hospital managers
- to request advocacy visits for the person they care for

**Mental Capacity Act 2005.**

Under this Act anyone caring for or supporting a person who may lack capacity, has the right to be consulted by professionals in assessing their capacity, as well as being involved in deciding what treatment or course of action is in the person's best interests. Carers also have the right to be named as the person's

Lasting Power of Attorney (LPA) and to apply (as a third party) for an independent assessment of whether the person they care for has justly been deprived of their liberty from the Court of Protection.

**National Service Framework for Mental Health (September 1999).**

This framework was the first of its kind to state the expectations of health and social services in England, as well as how changes would be planned, delivered and monitored. It is not a legal document but provides guidance and influences policy-making in the system, which may then impact (helpfully or unhelpfully) on the everyday experience of caring for an adult child with psychosis.

Within this framework, there is a section on 'Caring about Carers' (H.M. Government, 1999), which is focussed on three key aspects – information, support and care. This guidance links to the above acts and policies, in that it states that all individuals who provide regular and substantial care for a person on Care Programme Approach (CPA) should have an assessment of their caring, physical and mental health needs (repeated on at least an annual basis) and also have their own written care plan.

Further, it recommends that local health and social care communities should provide support for carers' groups and carers' centres, and develop local networks of support for carers. They should also ensure that carers from BME communities have access to information, are able to use culturally appropriate services, and have the opportunity to contribute to service planning and development, particularly pertinent in psychoses due to higher rates in these populations (Kirkbride et al., 2012). These communities, in particular are singled out as research and statistics shows that they are the least likely to proactively access mental health services and carer support (Carers UK, 2015a). The 'Caring about Carers' policy emphasises that not only should carers' needs be assessed but for care to be provided to meet these needs,

by mental health and social services, particularly for those caring for people with severe mental illness (SMI). As mentioned above, this framework has entered into the guidance for interventions used by the NHS, informing the National Institute of Health and Clinical Excellence (NICE, 2014) guidelines, which are described below.

### **NICE guidelines (2014).**

These guidelines recommend that carers supporting a person with psychosis, be offered an assessment of their own needs and develop a care plan with them, if needed, to be reviewed annually. Carers should be advised about their rights to a carer's assessment, their role in the care for the person they care for, the types of support available for them and be given education and support as early as possible (which may be part of Family Intervention). NICE guidelines (2014) advocate that mental health professionals promote a collaborative approach that supports both carers and the person they care for, as well as valuing their individual needs and interdependence.

## **2.8 Psychological models**

I will now move on to describe a psychological model of caregiving and a psychological intervention related to carers and psychosis. This will help the reader to understand a theoretical perspective on caregiving, as well as the therapies recommended by NICE for families of people with psychosis.

### **2.8.1 Cognitive model of caregiving in psychosis.**

Kuipers et al.'s (2010) model of informal carer relationships is based on the research around expressed emotions (EE). Carer burden is correlated with EE and high EE has been shown to be a predictor of outcomes and relapse in 'schizophrenia' (Raune et al., 2004). The model describes three pathways for three outcomes to develop: positive, emotionally overinvolved, or critical/hostile.

***Positive relationships.***

This describes relationships that were positive before the person developed psychosis. Caregivers see the illness as unusual and not a normal part of the person's behaviour, and so seek help early. They see the service user as a person, have positive appraisals of the psychosis and do not blame the recipient for their problems. As they tend to continue with their daily life, not abandoning work and other commitments to care solely for the person with psychosis, carers are less likely to become isolated. Carers are able to ask for help easily, engage constructively with services and possibly be helpful to other carers. Nonetheless, they still need information, advice and support, but may well be looked over by services as they are observed to be coping well.

***Emotional overinvolved relationships.***

This pathway is strongly associated with feelings of loss, self-blame and guilt about the recipient's 'illness'. As a consequence, the carer's life revolves around looking after the person with psychosis and finding a 'cure', often at a cost of other commitments such as work. Additionally, Kuipers et al. (2010) posit that these relationships are reminiscent of parents caring for a young child, with parents fixated on talking about how 'wonderful' their relative used to be. The recommendations for services are that interventions should focus on helping the carer to understand the service user as they are now and help them see what activities or tasks they are still capable of doing. This will enable the service user to regain their independence slightly, allowing the carer to find their independence outside of their carer identity. As these carers are likely to become isolated, services will need to support them in reconnecting with their network, as well as affording them the opportunity to look after themselves.

***Critical/hostile relationships.***

Kuipers et al. (2010) suggest that this pathway is characterised by poor early relationships and the service user likely having problems with substance misuse. As a consequence, they have a longer period of untreated psychosis as their difficulties will be attributed to the substance misuse. Carers are distraught when mental health services and professionals get involved, due to worries about stigma and shame of the psychosis. Their appraisals are likely to involve blaming the service user for their problems, placing the onus on them to get better and putting pressure on services to help. Overall, critical/hostile relationships are associated with negative reactions to the stress of the caring role compared to the other two pathways described. Carers feel angry, depressed and anxious, due to their sense of powerless to make a difference. They may engage in avoidant coping styles and unhelpful negative communication patterns with their relatives and services.

Of all three relationships outlined by Kuipers et al. (2010), carers in this pathway are the least likely to identify themselves as a carer. So, they will tend to reject information and support, particularly in the initial stages of their relatives' contact with services. Therefore, services will need to persevere and repeatedly give information to carers, as well as offering interventions for the family. This may help the family to understand that observed symptoms and behaviour are not the service users' fault, but part of the psychosis and improve communication.

This is a useful model to consider and is beneficial in understanding the context of caregiving relationships and the possible interventions or appropriate level of support that is needed. However, Kuipers et al. (2010) recognised that the models do not and will not fit all carers, due to the array of family structures and histories. Further, although this framework intimates that the 'quality' of the relationship

between the carer and recipient is a key factor, there is little reference or research as to what this 'quality' factor constitutes. Patterson et al. (2005) proposed that attachment theory (Bowlby, 1982) could be a useful framework for understanding caregiving in psychosis.

### **2.8.2 Psychological Therapies.**

With regards to interventions provided by health and social care services for people with psychosis and their families, most of them are focused on the person with psychosis (Yesufu-Udechuku et al., 2015). NICE guidelines (2014) recommend that carers and family members should be offered Family Intervention (FI), which is a psychological therapy. FI can include the person with psychosis if practical and appropriate. In this way, FI factors in the relationship between the carer/family member and person they care for. The intervention usually involves at least 10 planned sessions and lasts for between three months and one year. As mentioned earlier, part of FI is to have an educational, supportive, treatment function and includes problem solving skills or crisis management.

Despite FI being recommended by NICE (2014) as routine treatment, it is not readily available in all services due to a lack of resources regarding staff, training, time due to high staff caseloads and funding. Additionally, when these interventions are offered, the number of sessions that specifically include carers fluctuates and some clinical staff do not see it as 'their job' to offer direct help to carers (Yesufu-Udechuku et al., 2015). Kuipers (2010) suggested that this is due to a view that priority should be given to the person with psychosis and it is also complicated by the service user being an adult with associated confidentiality considerations. Indeed, there is limited focus on caregiver outcomes, which are often not reported (Kuipers et al., 2010; Yesufu-Udechuku et al., 2015). In contrast, in children and older adult

services, carers and parents' needs and wishes are taken into consideration by the team (Kuipers, 2010). This may be reflected in the relatively low uptake rates of FI in psychoses services, even in areas and services where FI is available and offered. A recent Early Intervention in Psychosis (EIP; HQIP and the Royal College of Psychiatrists, 2016) audit found that 582 families were offered FI, but only 38% of families took it up (62% declined). This strongly suggests that interventions currently being offered in services are not meeting carers' needs or expectations; however, it is not clear what these are with services having only a partial sense of what their experiences are.

*Carers being offered FI made my principal supervisor and I think about the implications of the carer position. Do they move from being a carer to a service user as well albeit in a different way? The policies described above seem to suggest that in some way they do. I wondered about what carers may feel about this, if they feel worthy of this input or want to be seen as coping rather than struggling by professionals. Could this be linked to why there is lower uptake of FI than one would expect?*

The next section presents a systematic review of the literature relevant to carers' experiences of supporting a person with psychosis.

## **2.9 Systematic Literature Review**

The introduction has given an outline of the area and I will now be exploring in greater detail the literature relevant to the research question. The aim of this literature review is to provide an overview and critical evaluation of the existing research relating to experiences of caring for a person with psychosis.

### 2.9.1 Literature Search Strategy.

To search and retrieve the journal articles for this review the following databases were used: Scopus, PubMed and APA PsychArticles, as well as looking at references lists of relevant articles. The search terms used for the review are presented in Table 1 below. These were chosen through trials of search terms aimed at gaining an understanding of which terms would produce the most inclusive and relevant results, combined with the terminology utilised by previous studies reviewed briefly in the initial literature search.

Table 1

#### *Literature Search Terms*

And	Not
parent* or caregiver* or primary caregiver* or carer* or father* or paternal or non-biological father	Physical Health or Disability
caring	
psychosis or schizopreni* or first episode psychosis or first-episode psychosis or severe mental illness or mental illness or mental health	
Child* or offspring or son or daughter or non-biological child*	

Using a combination of the terms in Table 1, the search generated 241 articles.

Once duplicate studies were removed, 233 papers remained. The titles and abstracts of these papers were then reviewed using the inclusion and exclusion criteria presented in Table 2. This left 25 studies.

Table 2

*Literature Search Inclusion and Exclusion Criteria*

Inclusion criteria	Exclusion criteria
Published in English	Not available in English
Peer reviewed paper	Non-peer reviewed paper
Studies attempting to look at the experiences of caring for a person with a severe mental illness/psychosis	Studies relating to mental health problems other than psychosis
Papers using qualitative and/or quantitative methodologies	<p>Studies relating to physical health, autism or disability</p> <p>Research on young carers' experience on looking after a parent with a mental health problem/parental mental health</p> <p>Studies relating to adult children caring for a parent (either due to ill mental health/ageing/dementia)</p> <p>Papers on experiences not relevant to present study (e.g. service users' experiences of psychosis, medical/genetic/biological studies)</p>

The full texts of the remaining 25 papers were read, producing eight relevant articles. A flow chart demonstrating the literature search process is presented in Appendix 1.

### **2.9.2 Overview of Findings from Systematic Literature Review.**

Following the strategy explained in the above sub-section, eight articles were identified for review. An overview of each of these studies can be found in Appendix 2. The quality of the research studies was assessed using two guidelines, by CASP, and Elliot, Fischer and Rennie (1999). It is beyond scope of the research to include this in the text, but a table can be found in Appendix 3.

All but one of the studies used a qualitative design, with the other utilising a quantitative methodology. Only two of the papers were conducted in the UK, with the remaining six papers conducted elsewhere, including the Republic of Ireland, Greece, Australia, Canada and the United States. Two studies appeared to have used the same participant group and data set, however, they were both included in this review as they had a marginally different focus. All of the studies assumed that the children or 'relatives' of the carers were biological related, unless stated otherwise and so the caregiving experiences are reported in this context.

I will discuss the key points and outcomes of each paper below; for ease of read, these have been divided by the focus of the research.

### **2.9.3 Experiences of caring.**

Five studies looked at primary caregivers' experiences of caring for a 'relative' with 'schizophrenia'; four of these used qualitative methodologies and one used a quantitative approach.

#### ***2.9.3.1 Parents' experiences of caring for a child with a 'severe mental illness (SMI)'.***

Using Thematic Analysis (Braun & Clarke, 2006) McAuliffe, O'Connor and Meagher (2014) explored the experiences of parents living with, and caring for an adult child with 'schizophrenia'. Six parents were recruited from the local mental health service, including five mothers and one father. The length of parents' caring roles varied from six to 25 years, capturing a breadth of experiences across the duration of their children's illnesses. This study reported the theme of a 'psychological tsunami' when their children were first diagnosed with 'schizophrenia', reflecting the trauma, shock and impact that parents experienced. They described an 'initial deep loss' followed by some form of acceptance. This was helped by the love

and responsibility the parents reported feeling for their child, which also gave meaning to their caring role. Responsibility was seen in a somewhat positive light, where the notion of their child representing a 'burden' was rejected by some mothers. It was not specified if the father in the sample also felt caring for his child was not a burden, or if he felt differently. This notion of burden and responsibility is viewed differently in the other studies discussed in this systematic review. In relation to coping with their caring role, participants reported finding relief in talking to other carers who could understand their experiences, a notion known as peer support. Interestingly, peer support was not highlighted in the other papers in this review, however, it was unclear why as other aspects of caring were reported.

In relation to mental health services, parents reported initially feeling dissatisfied with mental health professionals, which parents attributed to their own high EE, lack of knowledge about 'schizophrenia' and unfamiliarity with services. Nevertheless, at later stages of their children's 'schizophrenia' they were able to engage with services in a more helpful way, appreciating their support and advice, although the researchers did not elaborate as to why. This finding was similar to that reported by Raymond et al. (2017) but different to Sin et al. (2005) and McCann et al. (2011b), which will be considered later. The latter two studies only looked at experiences of FEP services at the start of the family members' psychosis (nought to two years), relative to the participants interviewed in McAuliffe et al.'s (2014) study (six to 25 years). There may be differences between the findings of the papers due to the stages of psychosis of their participants' 'relatives'.

Although this study adds to the limited body of research into the lived experiences of parents caring for a child with a psychosis-related difficulty, the sample is heavily biased towards mothers. The researchers commented that it was

very difficult to recruit fathers to the study, potentially feeding into the idea that men do not want to talk and/or are not involved in caring responsibilities. There is also a selection bias as parents were recruited from mental health services, so they were already linked in with professionals and most likely already identified themselves as carers. Further, this study accessed an Irish population, which may differ culturally or practically (as services may be set up differently) in their understanding and approaches to the treatment of psychosis-related difficulties, limiting its generalisability to the UK.

Similar themes and experiences from McAuliffe et al.'s (2014) study were found by Darmi and colleagues (2017). They used an IPA approach to explore parents' lived experiences of caring for a child with psychosis. Researchers interviewed 16 parents (14 mothers and two fathers). This was a large sample size for an IPA study (Smith et al., 2009). The superordinate theme 'Caring for an intimate stranger' captured the overall experience reported by participants. The authors suggested that the psychoses created changes in the parents' perceptions of their children, in their relationships with them and in their identity as a parent.

Unlike McAuliffe et al.'s (2014) finding regarding burden, Darmi and colleagues (2017) found that participants' sense of responsibility was fuelled by 'profound guilt' and self-accusation in failing to be a good parent to their child, and contributing to them developing psychosis. One wonders if this might reflect societal views that fuel experiences of stigma. There was an element of self-sacrifice reported by participants to compensate for this. The researchers suggested that it was possible that the sense of compensation and self-sacrifice was over-inflated by the high numbers of mothers and minimal fathers in the sample. Darmi et al. (2017) suggested that fathers might respond differently, and this required more exploration.

Additionally, the cultural contexts differed between the two studies (Irish and Greek populations); thus parenting and mental illness may be conceptualised by these societies in different ways, possibly explaining the different appraisals and responses.

As with the McAuliffe et al. (2014) paper, even though this study adds to the limited body of research on how parental carers make sense of their caring experiences, again the sample involved very few fathers. The researchers reported that fathers were unwilling to participate, providing little clarity as to whether they were involved in caregiving duties or not or if they did not wish to talk about their experiences. As explained in the paper this study was carried out in Greece, so it is possible that this may reflect cultural norms or practices where females are assigned the primary caregiving roles (Guberman et al., 1992)

### ***2.9.3.2 Caregivers' experiences of caring for a 'relative' with a 'first episode psychosis (FEP)'***

Themes of burden and self-blame also emerged in McCann et al.'s (2011a) research, however, there was also an emergence of positive aspects of caring. The researchers used IPA to understand the experiences of first-time primary caregivers of young adults with FEP. Six themes emerged, with the first three echoing what was found by McAuliffe et al. (2014) and Darmi et al. (2017). However, the latter three themes ('coming to terms with the change', 'becoming closer' and 'maintaining hope') appeared to encapsulate carers looking at the future and finding strength in feeling hopeful. The study highlighted that although caregivers spoke of their caring experiences being a 'roller coaster', they eventually came to terms with changes in the relationship with their 'relative'. This was reported to be to the extent where the relationship between carer and 'relative' became closer, which McCann et al.

(2011a) suggested was an unanticipated reward. However, this was in the context of the caregivers feeling a huge sense of responsibility for their 'relatives' illness'. This could have been because parents blamed themselves for their child's difficulties and also felt blamed by society, so they took extra responsibility to show that they care and are good parents. These findings are very similar to those reported by the other studies in this systematic review.

A strength of this study was its focus on lived experiences. It contributes to the limited research in this area, particularly in regard to the emergence of the positive aspect of caring for a person with psychosis. Nonetheless, there were some limitations of the work. Although this research utilised a good sample size (20 participants) for an IPA study (Smith, Flowers & Larkin, 2009), participants were predominantly female carers, who may have had different experiences to males. Moreover, the researchers provided no information as to how many mothers and fathers were in the sample.

As context plays an important role in facilitating and influencing how we make meaning (in line with a social constructionist position: Burr, 2015), the generalisability to the UK of McCann et al.'s (2011a) findings may be limited. As it was carried out on an Australian population of caregivers, their research may be bound to their context in regard to their understanding of mental health, concepts of caring and parenting and how services were set up at that time. Furthermore, the sample was specific to FEP, therefore the findings did not reflect or capture broader experiences, or how caring experiences may change over time as the psychosis-related illness progresses. Additionally, there was a potentially biased population, as the carers interviewed were already engaged with services. McCann et al. (2011a) suggested that the experiences of carers who were not in contact with services or had less

knowledge about psychosis may be different; however, they did not say why. It could be due to the way they appraised the psychosis, their role, and coping in alternative ways. Either way, it would be useful to investigate this further.

Even though Raymond et al.'s (2017) research was based on a US population, it was similar to McCann et al.'s (2011a) study, in regard to caregivers' initial shock and coming to terms with their relatives' psychosis. They examined how parents managed when caring for an adult child with 'SMI'. From the data collected through interviewing 30 parents, the researchers identified prolonged, difficult, and confusing phases that families go through in caring for a child with 'SMI'. The phases were progressive, for example, parents moved from 'recognising the illness', to 'scrambling for a diagnosis', to 'learning to manoeuvre the mental health system', and redefining family life. These findings were in line with the existing literature suggesting that parental needs differed within these various phases, therefore carers may need different types of support at these different stages. Despite this study adding to the limited body of qualitative research on parental carers experiences, the findings were somewhat limited by the methodology. Content analysis is a purely descriptive method and describes what is present. Nevertheless, it may not provide insight into the underlying reasons for the observed pattern; it focuses on the, 'what' but not the 'why' (Krippendorff, 2004, p18). As the analysis relies only on the words that participants used, linguistic and more conceptual elements of their narratives can be missed. Therefore, the level of detail obtained is limited and observations may not provide accurate portrayals of participants' realities. Furthermore, the analytic process can also bias the results as data is categorised in a particular way, for example, positive or negative. So, one category can outweigh the other, as well

as be influenced by the coders' perceptions of what positive and negative is (Krippendorff, 2004).

There were also difficulties in generalising the findings of this study to psychosis-related difficulties as the 'SMI' sample included 'schizophrenia-spectrum disorders' as well as bipolar disorder. Most participants' children had a diagnosis of 'schizoaffective' ( $n = 21$ ), followed by bipolar ( $n = 9$ ) and 'schizophrenia' ( $n = 4$ ). Caring experiences of bipolar disorder may potentially be very different to that of psychosis, as treatment guidelines, mental health services and understanding of these diagnoses differ. As with the other studies discussed here, there was a striking imbalance between the number of mothers ( $n=22$ ) and fathers ( $n=8$ ) interviewed in the study. Therefore, the potential differences in caregiving by gender are not reflected in Raymond et al.'s (2017) study.

### ***2.9.3.3 A quantitative perspective of the impact on families and carers.***

Addington et al. (2003) used a quantitative methodology to look at the correlations between the distress and impact that families of people with FEP experience when the client first comes into contact with mental health services for treatment. Participants were 236 family members, consisting of 173 mothers, 28 fathers and 37 spouses/other relatives. Researchers used the Psychological General Well-Being Scale (Bech, 1993) and Experience of Caregiving Inventory (ECI; Szmukler et al., 1996), regarded as the gold standard measure for caregiving in psychosis. The outcomes showed that all families were moderately distressed, with both measures being highly correlated. There was no difference in the level of distress and concern measured in carers who lived with their 'relative' and those who did not. Within the different sub-groups of carers, mothers scored higher on the ECI than spouses. However, there was no comparison between mothers and fathers.

Moreover, caregivers' psychological well-being was associated with their appraisal of the impact of the 'illness'. This suggested that mothers appraised their relatives' psychoses differently to the other types of carers, but due to the quantitative methodology used, there was no further exploration enhancing understanding. Interestingly, Addington et al. (2003) found that there were no differences in the 'relatives' symptoms of psychosis', regardless of whether they had family involved or not. However, in psychosis there is a value placed on the other difficulties that people may experience alongside their symptoms of psychosis, such as emotional distress (Schizophrenia Commission, 2012). It is recognised that the symptoms of psychosis may not change with treatment and support, but that the latter can help with the associated difficulties (Schizophrenia Commission, 2012). Therefore, it is possible that having family involved helps with the associated difficulties rather than the symptoms themselves, which may have not been captured by Addington et al.'s (2003) quantitative methodology.

Nevertheless, as it used the ECI, a strength of this study was its generalisability to other countries. This enables the consideration of how carers experience their role and how contexts may play a part in this. Inferential statistics were also used to determine the impact of patient characteristics on caregiving experiences. Despite the study representing a community sample, rather than a hospital sample, there was no information on the hours of contact between carer and recipient. The study was also carried out with carers at the start of their 'relatives' illnesses. Although, these were valid and important to capture, there was no longitudinal information on how these experiences changed at later stages of their 'relatives' psychosis.

No direct caring experiences were reported and there was no focus on the carers' lived experience. Further, in line with the limitations outlined with the above studies in this sub-section, fathers were again under-represented, with six times the amount of mothers compared to fathers. Additionally, the inclusion of various kinships within the study could have inflated the results.

#### **2.9.4 Experiences of mental health services.**

Two further qualitative studies looked at caregivers' experiences specifically in relation to FEP services, hence discussed separately to the above studies. As mentioned earlier, FEP carers may have different experiences and positions as they are relatively new to caring for a person with psychosis. Both papers used semi-structured interviews and analysed them using IPA.

From Sin et al.'s (2005) study, it emerged that all carers (seven mothers and four fathers) were providing a range of practical, emotional and financial support for their child. Although they liaised and engaged with mental health services, the researchers found that carers still felt invisible and undervalued by services with unmet needs in regards to information and support. The study suggested that due to a lack of training in their respective professions, mental health professionals do not feel skilled in handling the multi-faceted needs of carers and families. Additionally, they posited that the current service pathways were not accessible for families.

A similar theme emerged from McCann et al.'s (2011b) paper, where parents voiced the barriers they faced when engaging with FEP services, in particular issues of protecting their child's confidentiality (as they were technically over the age of 18), This has some connection to my earlier reflections (pg. 8). General practitioners (GPs) were also identified as potential barriers when accessing FEP services, which for some caregivers took several months. The interview data suggested this was

down to the limited understandings and knowledge of psychosis by GPs, and caregivers needing to be persistent in getting help for their 'relative'. This links with another finding that emerged from McCann et al.'s (2011b) paper, around knowledge and assertiveness enhancing access to mental health services. This put additional pressure on caregivers (namely parents) to act in an advocacy role, when potentially they were already struggling to cope with their caring duties, whilst also coming to terms with their 'relative' becoming unwell. Due to use of the same data, the limitations of McCann et al.'s (2011b) study were similar to the earlier paper discussed by the same authors (McCann et al., 2011a) (pg. 29).

Both of these studies focussed on parents' lived experience of FEP services, which adds to the limited existing literature into parental caring experiences. Nevertheless, both papers were specific to accessing FEP services, so provided less insight into the broader caring experiences and how these may change over time at different stages of the psychosis. Additionally, as both studies recruited from mental health services, it may have biased the findings given that the parents were already engaged in services and potentially already invested in their parenting and caring roles. The sample included more mothers than fathers, and as stated earlier (pg. 29), female carers/mothers may have different experiences to male carers/fathers. It is unclear from these two studies what the nuances were of these caring experiences. Nevertheless, Sin et al.'s (2005) research was UK-based, making it more generalisable to the current UK context than McCann et al.'s (2011b) study (see section 2.9.3).

I recognise that the wellbeing of people with psychosis who have no family involvement or who have familial histories such as neglect or abuse have not been addressed. Due to the scope of the current study, it was not possible to consider this

specific social context, however Bebbington et al. (2004) stated that families with a history of neglect or abuse would not usually be in caring roles, in line with Kuiper et al.'s (2010) model (pg. 18).

### **2.9.5 Experiences of hospitalisation.**

Hickman et al. (2016) also looked at parents' accounts for caring for a child with early psychosis, but specifically in relation to the experiential impact of hospitalisation. They used IPA, interviewing six parents (four mothers and two fathers). The themes indicated that even though parents felt negatively about certain aspects of hospitalisation, at the same time, they also felt relief, safety and containment. Parents' reported feelings about hospitalisation fits with the context of the studies discussed earlier, which highlighted parents' shock and trauma when their child first became diagnosed with psychosis or became unwell. The researchers also reported that parents blamed their child for their psychosis or did not believe that the psychosis was a legitimate 'illness' (in line with Kuiper et al.'s model of caring, 2010). This links with the concept of burden, and perhaps blame increased the sense of burden for parents in having to care for their child, whom they thought might have brought their difficulties on themselves.

Like Sin et al.'s (2005) and McCann et al.'s (2011b) studies, themes of feeling excluded, lack of information and feeling let down by services also emerged from Hickman et al.'s (2016) study. Furthermore, researchers found that parents spoke of worrying about the potential stigma of their child having psychosis and being hospitalised.

On the other hand, the implications of this study resonated with the current government mental health strategy, with regards to staff being 'carer aware' and receiving training in how to engage carers by focussing on inclusion, communication

and information sharing. As mentioned in section 2.8.2, this has not necessarily translated into practice. Being a UK-based study in the context of the NHS, the findings can be generalised more easily to other parental carers and mental health services in the UK. Another strength of Hickman et al.'s (2016) study was that it focussed on the lived experience of parents, through using IPA, which, in the context of mainly negative experiences, brought to light the 'relief' and containment that the parents felt when their child was admitted to hospital. Nonetheless, it was specific to parental experiences of their child's hospitalisation and so it provided less insight into broader caring experiences, for example, when the child is living at home or at later stages of the child's psychosis (as mentioned earlier in relation to FEP). It was possible that carers' meaning-making, appraisals of their caring role and child's psychosis, as well as their coping strategies, changed over time. It is important to capture these experiences given the enduring nature of psychosis-related difficulties and, hence, the caring role (Jungbauer & Angermeyer, 2002) with its associated costs. This is explored further in section 2.9.3. The sample was not homogenous as it included mothers and fathers, therefore it was difficult to discern the experiences between males and females (Smith et al., 2009). In relation to sample size, Hickman et al.'s (2016) study was similar to Sin et al.'s (2005) IPA research. This could be attributed to them both being UK-based studies and so, how fathers are perceived, involved in their child's care, and recruited into research studies may be different outside of the UK. This is promising given the current study is UK-based, as it suggests that paternal carers want to talk about their experiences of caring for a child with psychosis.

### **2.9.6 Synthesis of Findings**

The systematic review has provided an overview of the literature exploring caregivers' experiences of caring for a child or relative with psychosis.

The review clearly outlines that carers are heavily involved in caring and supporting their relative, and it is already known that this is the greatest source of management and support in psychosis (Kuipers & Bebbington, 1985). At the same time, similar themes from the reviewed studies highlighted that the impact of a psychosis-related diagnosis was not only traumatic for the person with psychosis, but also for their families. Several of the studies reported on the lengthy process and factors involved in accepting and coming to terms with the diagnosis, as well as the changes in the relationship with their child. Parents' sense of responsibility, guilt and burden around their child's psychosis-related difficulty were also themes that emerged from the studies reviewed, and often related to stigma, although one study actively rejected that experience of burden.

Other common themes that emerged from the reviewed studies were around the difficulties accessing support, in addition to frustration with mental health services. This was possibly associated with carers'/parents' lack of knowledge about psychosis.

One clear implication of this review was in the value for mental health services, including FEP services and GPs, to understand carers' experiences. There was agreement across of the reviewed studies that by doing this, services would be better able to meet carers' needs and support them, in line with current policies including the National Service Framework for Mental Health (H.M. Government, 1999). The findings for the studies in this systematic review heavily suggested that services have some way to go in doing this more consistently and proactively than is

currently occurring. Further, there were suggestions that services should be able to actually offer recommended treatments (e.g. NICE or equivalent), particularly around therapies, such as FI. I acknowledge that there are wider socio-political contexts and funding issues that impact on services' ability to do this. However, the importance of offering such interventions and support remains given the enduring nature of psychosis, and consequently the caring role. There were many implications to this; the emotional and psychological costs regarding distress to the person with psychosis and their system, the financial cost to the family and society, and the physical health costs to all involved. For example, service users have increased risks of physical health problems due to the side effects of antipsychotic medication (Muench et al., 2010) and carers' health can be impacted by the stress involved in supporting their relative (Jungbauer & Angermeyer, (2004).

### **2.9.7 Summary of systematic literature review.**

The review highlighted a lack of research adequately exploring the experiences of male carers and fathers, given all studies were heavily biased towards mothers. This may have not reflected the lived experiences of fathers and other male carers. Most of the researchers suggested that future studies should try to include more male carers and fathers, although acknowledged the difficulties in recruiting this sub-group of carers in research (McAuliffe et al., 2014; Darmi et al., 2017). They made reference to fathers having less contact with services as the mother was usually identified as the carer and point of contact, in addition to fathers not necessarily identifying themselves as carers, making it tricky to reach them and let them know about research studies. Darmi et al. (2017) suggested it could be linked with society's view on men not wanting to talk about their experiences and feelings, or that they should not talk about it. Additionally, research shows that fewer

fathers/male carers attend caring groups compared to mothers/female carers (Sharma et al., 2016).

As only two of the reviewed studies were UK based, it is imperative to mention the varied populations and countries in which the studies were carried out, particularly for the qualitative studies. As previously stated culture and context play a vital role in how people make meaning, due to differences in funding, service structures, differing roles due to cultural expectations (e.g. regarding gender or parental duties), and different conceptualisations of mental health and the language used to describe it. Therefore, this could influence how participating carers make sense and speak about their experiences.

Despite the rigorous search strategy (see flowchart in Appendix 1), a limited amount of literature on the lived experiences of parents, particularly fathers, caring for a child with psychosis was found, and very few that were UK based. It is possible, that literature pertaining to the topic may have been missed in the search process. Furthermore, not all reviewed research studies met all recommended quality standards (CASP; Elliot, Fischer and Rennie, 1999). The full quality check summary table can be seen in Appendix 3.

In conclusion, although some research has looked at caregivers' experiences much of this is based on the experience of maternal caregivers, thus, there is still a gap in the literature and our current knowledge regarding how paternal carers make sense of their caring experiences. By considering this, we may perhaps be able to strengthen the potential for carers to make a positive impact on the care of their adult children and also identify ways the system can support those undertaking this potentially important role.

**2.10 Research Question.**

In view of addressing the gap in the existing literature relating specifically to fathers' caring experiences, the main research question is:

What are the experiences of fathers caring for an adult child with psychosis?

## CHAPTER 3. METHOD

The aim of this study was to explore fathers' experiences of caring for a child with psychosis. The following section describes the methodology used to meet these research aims as well as the rationale for this. Details of participants, recruitment process, ethical considerations, data collection and analysis are also outlined.

### 3.1 A qualitative approach

Due to the limited research related to fathers' experiences of caring for a child with psychosis, this study focussed on exploring a deep account of fathers' lived experiences of being a carer, using a qualitative methodology. Qualitative methods are good for exploratory research and allow for a person's experience and understanding to be analysed in detail (Barker, Pistrang & Elliot, 2002) as well as giving space for complex and rich information to surface. Therefore, a qualitative approach was chosen for this study due to its suitability in fulfilling the research question.

### 3.2 Consideration of other methodologies

A quantitative approach and a range of qualitative methodologies were considered for this study. These are briefly described below, and this section concludes with the rationale for the methodology that was chosen.

Quantitative approaches seek to quantify a phenomenon e.g. attitudes, opinions and behaviours, by generating numerical data, through structured questionnaires, surveys and polls, or transforming data into operational statistics (Fields, 2009). Usually, quantitative studies involve a large sample representing the population being investigated. The findings tend to be conclusive, with recommendations for a particular course of action, as well as generalisation to a larger population (Fields, 2009). As such, there is no focus on understanding

peoples' lived experiences, as evidenced by Addington et al.'s (2003) study discussed in the systematic review, which used a quantitative methodology. However, on occasion quantitative research can be followed by qualitative research, which can be utilised in order to investigate the outcomes in more detail. Overall, a quantitative methodology was not deemed suitable in answering the research question for the current study, which focuses on participants' direct lived experiences. A number of qualitative methodologies were considered initially:

Narrative analysis (NA) is mainly concerned with making sense of people's stories and how these stories have developed over time (Emerson & Frosh, 2009). Although this seemed like a potential and feasible methodology option for this study, NA focuses on the content and structure of the stories that people tell (Reissman, 2008). As this project was primarily interested in the meaning-making processes of participants' experiences, a methodology more in line with the research question was sought.

Grounded theory (GT) enables theory development as it looks at how social processes happen within particular contexts (Glaser & Strauss, 1967; Charmaz, 2015). Although GT uses interpretations, it has a more sociological focus, whereas this study has a psychological focus, looking at participants' lived experiences. In addition, GT needs a large sample of participants so that theories can be generated. This would have been problematic with the small, homogenous sample that was anticipated to be recruited for the study. Given the experiences from previous studies of recruiting fathers, there were concerns about the logistics of recruiting enough participants in the limited time available. Therefore, GT was not an appropriate methodology for this study.

Thematic analysis (TA) is a flexible approach, identifying and examining patterns and themes within data, which are important to the description of a particular experience or research question (Braun & Clarke, 2006). TA was considered too descriptive and broad for this study, so a methodology allowing more in-depth analyses and interpretations, particularly in relation to fathers' lived experiences was sought.

Discourse analysis (DA) focuses on the structure and use of language in the construction of social reality (Edwards & Potter, 1992), providing a way to examine how people make sense of themselves as well as the world around them (Shotter, 1993). As DA is mainly concerned with social processes and discourse (Willig, 2013), rather than meaning-making, it was not deemed an appropriate methodology for meeting the study's research questions.

Therefore, as the purpose of IPA is to explore and analyse how people apply meaning to major life experiences and how they make sense of them, an Interpretative Phenomenological Analysis (IPA) was chosen as the most appropriate methodology for this study's research question.

### **3.3 Interpretative Phenomenological Analysis**

IPA is an approach that focuses on the details of people's lived experiences, offering a recognised, phenomenologically focussed approach to the interpretation of these accounts (Larkin & Thompson, 2012). IPA was developed in 1996 and to begin with was primarily utilised in health psychology research. This has now expanded to being employed, more broadly in many different research areas (Wagstaff et al., 2014). For the reader to gain a deeper understanding of IPA and its appropriateness for the current study, I will now describe its theoretical underpinnings, focussing on

phenomenology, hermeneutics and idiography. This will be followed by a summary of the strengths and weaknesses of this methodology.

### **3.3.1 Phenomenology.**

Phenomenology is an approach that concentrates on studying consciousness, direct experience, and how a person engages with the world around them (Smith et al., 2009; Finlay, 2011). Therefore, IPA focuses on examining peoples' lived experiences, taking into account their context and relationships to obtain an insider perspective (Smith & Osborn, 2003). As such, the researcher is required to consider and handle participant data with the purpose of understanding participants' world. In line with this, they need to carry out their analysis by placing participants' experiences in their wider societal, cultural and theoretical contexts (Larkin, Watts & Clifton, 2006). The focus on important individual experiences fits with the current research question, which explores the caring experiences of fathers.

### **3.3.2 Hermeneutics.**

According to Smith (2007), hermeneutics refers to theories of interpretation, with the emphasis on how meaning is made and explained through experience. Its foremost contributors were Husserl and Heidegger and it has grown with application to a broad corpus of research areas (Porter & Robinson, 2011). As IPA utilises interpretation to bring to light meaning and sense-making in peoples' experiences, the researcher has a role in facilitating, and potentially influencing, this process. Therefore, IPA is said to involve a "double hermeneutic" (Smith & Osborn, 2003, pg. 3) as the interpretative aspect involves an interplay between the researchers' assumptions and biases and how they receive information about participants' experiences. Therefore, as the researcher for the current study, I have attempted to make sense of participants' experiences, who have attempted to make sense of their

own caring experiences. As such, IPA consists of a co-construction of participants' experiences, where their meaning-making is seen as first order and my sense-making is second order (Smith et al., 2009). Therefore, it is imperative for researchers to engage in continual processes of reflexivity to identify their contribution to the interpretative process and reflect on their own biases, assumptions and values (Larkin & Thompson, 2012).

### **3.3.3 Idiography.**

Idiography is concerned with the particular rather than the general (Smith et al., 2009) and does this in two ways. One is regarding the detail and depth of analysis of participants' experiences and the second is through understanding how an individual experience has been made sense of by a particular person, within a particular context (Smith et al., 2009). For IPA to achieve this, smaller sampler sizes are more suitable, so that a more in-depth analysis can be carried out. Nonetheless, IPA acknowledges that there is more than one route to learning about an individual's direct experience and maintains that research should focus on being 'experience close' rather than 'experience far' (Smith, 2011).

### **3.3.4 Strengths of IPA.**

A strength of IPA is its positioning of participants as the experts of their experiences; the sharing of these with researchers then provides insights into them. Further, IPA enables new, rich and unique understandings and perspectives due to its idiographic nature and consideration for how certain events are made sense of by an individual at a certain time (Smith et al., 2009). Moreover, the awareness of IPA's 'double hermeneutic' enables the researchers' involvement and influence to be taken into consideration in relation to the interpretative aspect of the participants' data (Willig, 2013). Also, novel researchers have the opportunity to utilise the IPA

methodology with the comprehensive and explanatory guidance provided by Smith et al. (2009).

### **3.3.5 Weaknesses of IPA.**

Despite the numerous strengths of IPA, there are limitations. IPA is a fairly new analytic method, and even though Smith et al. (2009) provides guidance on IPA, researchers can experience difficulties in conducting the analysis (Wagstaff et al., 2014). Along with students using IPA, who can struggle to implement and carry out IPA, this has led to some studies not being representative of high quality IPA (Hefferon & Gil-Rodriguez, 2011).

Further limitations were identified by Willig (2013) around language, a lack of theorising reflexivity, and description over explanation. As already highlighted, language is a fundamental and integral part of IPA. As such, the analysis requires, and is reliant on, participants to be able to offer rich and in-depth descriptions of their experiences (Smith et al., 2009). However, for some people this may be difficult, particularly in the context of complex or challenging experiences. People with cognitive and/or speech difficulties or with English as a second language may also struggle with providing detailed accounts of their experiences. In turn, this may limit the analysis in its ability to encapsulate the subtleties of experiences and phenomenological differences across the data set. This may result in a more descriptive analysis than an analytical one, highlighting the limitation of IPA's reliance on language. Further, IPA's terminology appears to conflict at times with its theoretical underpinnings, in regards to terms such as 'emerging themes'. This term implies a nature of a phenomenon being unearthed rather than a process of co-construction, with the latter being in line with IPA's double hermeneutic discussed earlier. In this way, according to Willig (2013), despite IPA recognising that the

analysis is a process of the researcher making sense of participants' own understanding of their experiences, there is a lack of clarity in how researchers can limit the impact of their influence on the data. Additionally, Willig (2013) questions the breadth of what can be discovered from IPA, as the analysis does not account for historical or contextual dynamics, which undoubtedly will influence participants' worlds. As phenomenology focuses on people's direct experience, relying on their descriptions of their world as it is now, there is little if any focus on the explanation of how their world came to be viewed in the way they describe.

As the researcher, I endeavoured to be mindful of these limitations over the course of this study, in particular during the analysis of the data. This involved recognising the double hermeneutic between participants and myself, adhering closely to Smith et al.'s (2009) guidance, engaging in reflexivity, and utilising research supervision appropriately.

### **3.4 Participants**

#### **3.4.1 Recruitment.**

A purposive sampling method was used to recruit fathers caring for a child with psychosis. The aim was to recruit six to eight participants following the recommended sample size for IPA (Smith et al., 2009).

There were several facets to the recruitment strategy of this study, in a bid to reach as many potential participants as possible. One strategy was to approach carers' organisations and carers' groups in the voluntary, charitable and third sectors, both locally and across the country. No specific geographical area was identified due to the anticipated difficulties in reaching fathers who were caring for a child with psychosis and recruiting them to participate in the study. This was based on the reported difficulties of recruiting this participant group (as suggested in the

systematic literature review) and the subsequent lack of research in this area.

Additional local groups and agencies were identified following recommendations from the secondary supervisor of this project who works in this field. Another strategy was to approach the Service User and Carer Committee, which is linked with the Hertfordshire doctoral psychology course. Members of this committee offered additional suggestions for local groups and forums that I could approach to promote the study.

In addition to the above strategies, an amendment was applied for and approved by the University ethics committee to include the snowballing effect (see Appendices 4 and 5). This was to enable people attending the carers groups and fathers who had already taken part in the study to tell other fathers they may know, who may not necessarily attend carer groups, about the research.

The leads of carer groups, forums and organisations were emailed with a summary of the study (see Appendix 6) with a copy of the information sheet and consent form (see Appendix 7). With regards to the carers group, I requested to join these either at the beginning or end (only if appropriate) to talk about my research. I felt this step was important as face-to-face contact can make a big difference in how carers hear the research and decide whether to participate. It also gave them the opportunity to ask me questions directly. Participants who were interested in hearing more about the study or willing to be interviewed were able to contact me directly via my university email address. Once they contacted me, I arranged a time to speak to them on the telephone to check their suitability for the study, answer any questions they had and if appropriate arrange a time to interview them.

Even though I felt the face-to-contact was imperative in recruiting fathers to the study, via attending carers' groups, I often felt conflicted by this. I was aware of how important these groups and spaces were to carers for seeking support for themselves. Therefore, I felt somewhat selfish and guilty that I would be taking 'some of their time' away to talk about my research. I always discussed this with the group lead/facilitator prior to attending to negotiate how best this could be done e.g. asking the attendees if it was okay for me to come and whether it would be better for me to join at the start or at the end. Knowing that attendees were on board with me coming, made me feel at ease. I was also reassured by the initial feedback that I received from the carers, in that they were pleased that research was being done in this area and showed interest in hearing the outcomes of the study.

### **3.4.2 Inclusion and Exclusion criteria.**

To be eligible for the study, participants were required to be a father or father-figure caring for a child (18+) with a psychosis-related diagnosis and fluent in English. As there is a huge emphasis on language in IPA and resources were restricted regarding employing interpreters, participants who could not speak English were excluded from the study. Participants' suitability for the project was determined through an informal telephone conversation before being recruited.

### **3.4.3 The Sample.**

A total of seven participants were recruited for this study, in line with the recommended sample size for IPA (Smith et al., 2009). Of the seven participants, six were the biological fathers of the child they cared for and one was a stepfather, who cared for two children with psychosis-related difficulties. All participants had other children. Only one participant lived with the child they cared for, with all other

participants living separately to their child with psychosis. All participants had been or currently were the main earner in their families. Three participants were currently employed and three were retired with jobs ranging from lawyer, engineer and bank manager. One participant was unemployed due to a long-term disability. Participants had been carers for between two and 30 years, with an average length of caring time of 15 years. Participants spent an average of 17 hours per week caring for their child. All participants had experiences of the NHS as their children had been under mental health services. Two of the participants had previously had psychological therapy in the form of FI. The demographics of the recruited participants is presented below in Table 3.

Table 3

*Participant Demographic Information*

Participant Pseudonym	Age	Ethnicity	Marital Status	Relationship to child	Length of time in caring	Participants' Description of Child's Mental Health Difficulty
Victor	56	White British	Married	Father-Daughter	13 years	Psychosis Autism
Leo	63	White British	Married	Father-Son	11 years	Paranoid Schizophrenia
Ron	69	White British	Married	Father-Son	22 years	Schizophrenia
Neil	65	White British	Married	Father-Son	2 years	First-episode psychosis
Bryan	67	White British	Married	Father-Son	16 years	Paranoid Schizophrenia
Paul	53	White British	Single	Stepfather-son Stepfather-son	10 years	Schizophrenia Schizophrenia
Patrick	62	Mixed Caribbean	Married	Father-Son	30 years	Schizophrenia Personality Disorder

### **3.5 Ethical Considerations**

The study was granted full ethical approval by the University of Hertfordshire's Health and Human Sciences Ethics Committee. The ethics application was amended to allow for a greater number of participants to be recruited, which was approved (Appendices 4 and 5). The protocol number was: aLMS/PGR/UH/02801(2). The following areas were thought about as part of the ethical considerations.

#### **3.5.1 Informed consent.**

All participants were given an information sheet (Appendix 7) and full explanation of the research project as well as the opportunity to ask any questions. In order for participants to take part in the study and be interviewed, they were required to sign a consent form (Appendix 7). All participants were made aware that they had the option to withdraw their consent from the study at any time for any reason, and this would have no impact on the quality of care which either themselves or the person they cared for received from services. Informed consent was obtained from the participants for their interviews to be audio-recorded.

#### **3.5.2 Confidentiality.**

The parameters of confidentiality were outlined in the information sheet and communicated verbally to participants prior to carrying out the interviews. It was explained to all participants that the only exception to upholding confidentiality would be if any risk issues were raised (which did not occur within this study). Additionally, all interview data was kept securely, anonymised and no identifiable data was used during the analysis or write-up of the thesis. Data was transferred via secure means between the professional transcription service and myself. As part of this process a non-disclosure agreement was signed by both parties (Appendix 8). I transcribed one interview and the transcription service completed the remaining six.

### **3.5.3 Potential distress.**

I was aware that interviewing fathers about their experiences of being a carer could elicit some level of emotion or distress. Prior to carrying out the research interviews, I completed a pilot interview with a carer consultant, to ascertain the appropriateness of the questions in the interview schedule. The consultant's feedback informed me that the questions were suitable and not particularly upsetting to think about and answer. In order to support participants during the interview process, they were able to decide whether to answer a question or not, as well as the option of ending the interview at any point (which was outlined in the information sheet and re-iterated at the start of all interviews). When participants did become emotional or tearful during the interviews, I used my therapeutic skills as a Trainee Clinical Psychologist to empathise, and assess whether they were happy to continue with the interview. To support the carers after the interview process, they were given the opportunity to ask me any questions, feedback and a debrief (see Appendix 9), as well as signposted to local support organisations if necessary.

### **3.6 Carer consultation**

I believed it was essential to consult with a carer for feedback on the study in general, its design and interview schedule. This is in line with the NHS Patient and Participant Involvement policy (DoH, 1999) and Research Governance Framework for Health and Social Care (DoH, 2005), stating that involving service-users and carers in research is imperative in developing the NHS and related healthcare services. Further, benefits of being included in research has been reported by experts by experience and researchers (Faulkner 2012).

As I was already in touch with the Service User and Carer Committee (which is connected to the Hertfordshire doctoral psychology programme) for the

recruitment aspect of the project, I also approached them to find a parent caring for a child with psychosis, who would be willing to consult on the study. As fathers were anticipated to be difficult to recruit, it did not seem feasible to employ a potential participant as a consultant for the project. Thus, the consultant was a mother and not a father, who was a long-term carer for their child with psychosis. It was decided, in conjunction with my supervisor that a mother's perspective would suffice for the carer consultant role, as they would still be able to share their knowledge and experience. This consultant aided the study by reviewing all of the resources, including the information sheet, consent form and the interview schedule, and by participating in a pilot interview, which will be described in a later section.

Throughout the process of consulting with this carer, I was mindful of the pressure the role may place on her, especially in the context of her caring responsibilities.

Therefore, from the start we negotiated the specifics of the role and the anticipated time that it would take, whilst I also regularly checked in with her during the consulting process. This appeared to be received positively by her, and may have influenced her feedback, which I found to be very useful.

### **3.7 Data Collection**

#### **3.7.1 Interview schedule.**

As language is key in qualitative research (Barker et al., 2002) and the interview schedule should enable a conversation (Biggerstaff & Thompson, 2008), much thought was put into developing the interview schedule. A semi-structured interview schedule was developed in conjunction with my principal supervisor, using guidelines by Smith et al. (2009). This was then refined from discussions with my secondary supervisor and carer consultant, and by using feedback from the pilot interview. The interview schedule was based on open-ended questions as the aim

was to enable participants to freely give their perspectives and encourage them to talk specifically and in detail about their experiences, thoughts and feelings. A copy of the interview schedule can be found in Appendix 10.

### **3.7.2 Pilot interview.**

As mentioned, a pilot interview was conducted with the carer consultant. This was to check how being asked and answering the questions on the interview schedule was experienced by the carer, as well as more general feedback on being interviewed. The pilot interview took place at the University of Hertfordshire, a familiar location to the carer. She consented to taking part in the pilot interview, however did not consent to it being audio-recorded, therefore I made notes. After completing the interview, I asked her for feedback on the content and process of being interviewed, as well as suggestions for changes. Overall, the consultant believed that the questions were open-ended and touched on the key areas that were important for carers to be asked about and talk about. The feedback from the pilot interview was used to change the order and wording of a few of the questions, however, most of the interview schedule remained unchanged.

Further, the pilot interview enabled me to practice my interview and questioning skills in a research capacity. In particular, it allowed me to experience and consider my style of questioning and how I responded to the carer in the moment. I believe this reflexivity was important given that inflexible questions in initial research interviews are often used by inexperienced or new qualitative researchers (McNair, Taft & Hegarty, 2008), potentially leading to low quality IPA research.

From conducting this pilot interview, I noticed that the carer talked a lot about her child rather than her own experiences, despite the questions asking specifically about the latter. It made me wonder about how difficult it must be for carers to talk about their own experiences and the little opportunities that they may have to do so. It reminded me of an earlier experience of doing an assessment with a carer when I was an Assistant Psychologist, who struggled to complete a questionnaire on their own well-being. They told me that no one ever asks about them and if professionals want to speak to them, it was always in reference to their child - how do they think their child is doing? What do they notice about them? What do they think will help? I felt saddened by this, but also became aware that this could be an issue that arises in my research interviews. I discussed this with my principal supervisor and we agreed that I needed to keep an ear out for when carers start talking about their child and not about themselves, and find ways to gently prompt them to focus on their experiences.

### **3.7.3 Procedure.**

Participants were given the choice of where they would like to be interviewed. Research shows that the environment plays a role in enabling sharing experiences (Riessman, 2008), therefore if participants were comfortable and at ease, they would be able to speak more easily and in depth about their experiences. Further, given the caring responsibilities that the participants held, it was important to be flexible and go to the carers' choice of location, at times that fitted in with their caring duties. Six participants chose to be interviewed at their home and one in a community centre. Interviews lasted between 60 and 90 minutes, and were audio-recorded and later transcribed.

After each interview, I reflected on my experience and feelings before, during and after the interview, to consider what influence this may have had on the interview process and how participants spoke of their experiences. These reflections were added to my research diary, some of which have been shared in this thesis.

### **3.8 Data Analysis**

The interviews were analysed using IPA as described by Smith et al. (2009), and supervised by an experienced IPA researcher (the primary supervisor of the study), who was also involved in quality checks at various points during the analysis. This was an integral part of the analysis process as it ensured that the themes and analysis remained grounded in the participants' words and experiences, without being biased by my own assumptions and values.

#### **3.8.1 Individual case analysis.**

As IPA is idiographic in nature (Smith & Osborn, 2008), the first step involved analysing each transcript individually. This involved reading each transcript multiple times and formatting each transcript to include two columns on either side of the interview text; the right hand column was for noting my reflections and the left for developing emergent themes. Whilst reading and re-reading the transcripts, I also listened to the interviews to 'immerse' myself in the participant's world (Smith & Osborn, 2008). In keeping with the guidance of Smith et al. (2009), the aim of this initial process was to ensure that the participant remained the centre of the analysis. Following this, I went through the transcript line-by-line, making notes on linguistic, semantic and conceptual aspects of the language. Words, phrases and comments in the text that stood out to me were also highlighted. An extract of a transcript can be found in Appendix 11, demonstrating this process.

The next stage of analysis looked to construct and identify the emerging themes. This process involved condensing the amount of data, whilst retaining the quality of it and staying close to the participant's words and experience (Smith, 2011). In keeping with the IPA approach, I strived to use participants' words in developing and naming the emergent themes. Emergent themes were then analysed for their connections and 'clustered' together to reflect an overview of the participants accounts, as well as key, specific aspects of them. This was guided by Smith et al.'s (2009) techniques of abstraction, numeration and polarization, which were also used to identify and define the superordinate theme within each cluster. Extracts from the transcripts and quotes representing each theme were chosen, thereby ensuring that the themes were grounded in the participant's words and experience and assisting the write up of the results chapter. An example of this process is presented in Appendix 12, which shows the identified emerging themes in a transcript, and the clustering of these themes with associated quotes.

### **3.8.2 Cross-case analysis.**

This stage involved looking at all the themes for each participant to identify patterns, connections, convergences and divergences across the data set, to form the superordinate and subordinate themes (Smith & Osborn, 2003). This process involved re-reading the transcripts to highlight the superordinate themes at the group level and to continue to ensure that themes were grounded in the participants' experiences. After this, a list of the superordinate and subordinate themes for the whole data set was composed, which was used as a framework for writing up the results chapter (see Appendix 13). A process of cross-referencing the themes was also carried out to further highlight the themes of the data set (Appendix 14).

### **3.9 Quality of Qualitative Research**

Given quantitative research is based on standardisation and identifying an objective truth (Barker et al., 2002), I acknowledge that the guidelines it uses to evaluate objectivity, validity and reliability cannot be applied to qualitative methodologies, due to fundamental epistemological differences. Nonetheless, due to the rise of qualitative methodologies in research, it is important to demonstrate the credibility and rigour of qualitative studies. There are various guidelines that have been developed to assist in the evaluation of the qualitative research studies (Elliot, Fischer & Rennie, 1999; Yardley, 2000; 2008; Tracy, 2010; Spencer et al., 2003). The principles proposed by Yardley (2008) were used for this study as it has been used by many IPA studies previously and is recommended for considering the validity of an IPA study (Hefferon & Gil-Rodriguez, 2011). There are four principles include: sensitivity to context, commitment and rigour, coherence and transparency, and impact and importance. A further evaluation using Tracy's (2010) 'Big Eight' was used to assess the quality of the current study, which will be referred to in the discussion (see Appendix 15).

#### **3.9.1 Sensitivity to context.**

As Yardley (2008) posits, showing sensitivity to context is key in demonstrating the validity of a qualitative study. In the current study, this was done in a number of ways. Firstly, a systematic literature review was completed to gain an awareness of previous and current understandings of the research area, and to identify a gap in knowledge, a process which contributes towards forming the research question. Additionally, the introduction chapter describes relevant policies, guidelines and models pertinent to the socio-cultural context of carers of people with psychosis. Further, employing a carer consultant and conducting a pilot interview

allowed for assessment and awareness of the relevance and sensitivity of the interview questions. Participants were given a choice as to where they wished to be interviewed, while to ensure transparency and sensitivity to context further, I invited participants to ask me any questions, as well as offering breaks during interviews if required.

Using an IPA approach assisted in maintaining sensitivity to participants' contexts, due to the idiographic nature of this methodology, which valued the interactional aspects of the data (Smith et al., 2009). I also strived to be mindful of what participants said and did not say. Extracts and quotes from participants' interviews were included in the write up to support the emerging themes, alongside re-reading transcripts to ensure sensitivity to the data.

### **3.9.2 Commitment and Rigour.**

In the current study, commitment and rigour were demonstrated by carrying out a comprehensive analysis to add substantial insights to the research question (Yardley, 2008). This was done by immersing myself in the data, applying the IPA model according to Smith et al.'s (2009) guidelines, supervision from an experienced IPA researcher, being part of an IPA-focussed peer-supervision group and receiving some teaching sessions on IPA. In addition, the principal supervisor carried out quality checks by reviewing three full transcripts that I had analysed, and largely agreed with the emergent themes.

Developing an appropriate open-ended semi-structured interview schedule with my supervisors and carer consultant was another way in which this study demonstrated rigour. Further, homogeneity and suitability of participants was assessed by informal telephone conversations prior to arranging an interview slot. The use of a reflective diary through the data collection and analysis processes

enabled me to bracket my experiences, as well as informal discussions with my supervisor (Ahern, 1999) about my own assumptions and values (Appendix 16).

Additionally, as mentioned earlier, the ethical application process to the University of Hertfordshire's Health and Human Sciences Ethics Committee, ensured rigour in being aware of the ethical issues surrounding the study.

### **3.9.3 Coherence and transparency.**

Coherence in qualitative research is associated with having a firm grounding in the methodological approaches utilised and their theoretical background (Yardley, 2008). Transparency relates to how well a reader is able to see why and how a research study was conducted (Yardley, 2008). Both coherence and transparency were shown in the current study in a variety of ways. Initially, the introduction and systematic literature review provided the rationale for the research question, followed by providing a rationale for why IPA was chosen, including its limitations and a consideration of other qualitative methodologies. In addition, having direct clinical experience of working in this area also gave me an awareness of the service and carer contexts, which has been outlined in my personal position. This, along with describing my epistemological position offers transparency to the reader, so that they have an understanding of my context, perspective and values. At the same time, keeping a reflective diary throughout the research process supported me to be transparent and limit my own assumptions and beliefs influencing the data (see Appendix 16). As excerpts of this diary have been included in this write up, this added another layer of transparency to this study.

Employing an IPA approach has enabled a transparent analytic process, which has been demonstrated by an excerpt from a transcript and audit trails in the appendices (see Appendices 11, 12 and 13). I hope this allows the reader to gain a

thorough understanding of the analytic process, including the development of superordinate and subordinate themes. This has been further enhanced by the use of verbatim quotes and extracts from participants' transcripts throughout the results chapter.

#### **3.9.4 Impact and importance.**

According to Yardley (2008) validity ensures a study's potential to make a difference, its' impact and ability to inform the reader of something useful and interesting. The paucity of research relating to fathers' experiences of caring provides a robust rationale for the study. It also suggests that the findings may be important in impacting on carers, mental health professionals and service users. The discussion chapter will talk more explicitly about the clinical implications and recommendations. I endeavour to prioritise dissemination through carers groups and organisations, as well as publication in a peer reviewed journal.

## CHAPTER 4. RESULTS

This chapter reports the outcomes of an IPA process of seven interviews exploring fathers' experiences of caring for an adult child with psychosis.

The following five superordinate themes emerged from the analysis:

1. Father vs. carer
2. Change in quality of relationship with child
3. To share or not to share
4. Acceptance is a struggle
5. Mental health services: Inconsistency vs. luck

The themes presented in this section offer one possible account and construction of fathers' experiences of caring for a child with psychosis. I acknowledge the role of my own meaning-making in interpreting the words of the participants and the influence of this on the analytic process and results. I have tried to make sense of the fathers' attempts to portray and understand their caring experiences, which informs the double hermeneutic intrinsic to IPA (Smith et al., 2009). It is impossible to exclusively identify the impact of my values, assumptions and epistemological position, thus, the results are "socially-constructed, partial and incomplete" (Smith & Osborn, 2008, pg. 51). I am also aware of an extra layer of the hermeneutic process, in that readers will be forming meaning based to a degree on their own interpretations of the data. I have made every effort to provide a systematic and representative narrative account of the participants' experiences.

Verbatim quotes and extracts from participants' accounts are used to illustrate the themes, the relationships between them and outline the validity of the research. To protect confidentiality, pseudonyms are used and all participant data has been

anonymised. For ease of readability repeated words and fillers (e.g. 'erm') have been removed, indicated by ellipsis '...' or curved brackets (), and where material has been inserted into the text to clarify a missing point this is indicated by closed square brackets [ ].

I acknowledge that due to space limitations and the scope of this thesis, the extent to which the ideas, opinions and experiences the seven participants are shared is restricted. An overview of the themes for each participant is provided in Appendix 13.

I have endeavoured to illustrate the experiences and perspectives of each participant, and balanced these with more generalised theoretical insights, as suggested by Smith et al. (2009). Additionally, the extent and ranges of convergence and divergence, within and across, both the themes and participants' accounts have been attempted to be elucidated in this section.

A summary of the superordinate and relating subordinate themes is presented in Table 4 below. This is followed by a detailed account of each of the themes.

Table 4

*Superordinate and subordinate themes of IPA account*

Super-ordinate Themes	Sub-ordinate Themes
Father vs. carer	<p>I'm a father first</p> <p>As a father, you would do anything for your child</p> <p>Being a parent can hinder caring role as you are too emotionally close</p>
Change in quality of relationship with child	<p>For better or worse</p> <p>Protecting child vs. looking after self</p> <p>Spending quality time with <u>all</u> your children/Shared interests are important</p>
To share or not to share	<p>Sharing eases isolation</p> <p>Sharing is risky</p>
Acceptance is a struggle	<p>A double-edged sword: Feeling helpless</p> <p>Trying to make sense of why and how this happened to my child</p> <p>Hope vs. Loss</p>
Mental health services: inconsistency vs. luck	<p>When services get it right, it can be life-changing for child and family</p> <p>Services supporting child support parents</p> <p>We need to advocate for our child to get the help they need</p>

## **4.1 Father vs. carer**

This superordinate theme referred to how fathers viewed their roles as a parent and a carer. This comprised of the expectations and responsibilities involved in being a carer and how this hugely overlapped with, if not encompassed, what it meant to be a father. Participants talked about their views of being a carer in terms of this being part and parcel of being a parent, even though it was difficult and stressful at times.

For some participants, being a father had helped to take on the role of a carer, in that they knew their child better than anybody else, and used their parental instincts to guide their child. However, other fathers identified difficulties with the dual role of being a parent and carer which complicated the emotional side of caring for their child with psychosis.

### **4.1.1 I'm a father first.**

This subordinate theme reflected participants' views and positions on how they saw their role as a parental carer. Patrick described it as:

you're a father first, you only become a carer because you have to...first of all, you're a parent, and if you're a good parent, you should be a good carer.

This was echoed by Bryan, who believed there was an enormous overlap between being a father and a carer. The way Patrick repeated the role he has ("father", "parent", "carer") emphasised its importance and its interrelatedness. Simply by being a father first, he became a good carer, highlighting that from his experience, he felt that the skills needed to be a good carer are the same skills that one needs and uses to be a good father to his child. These quotes appeared to

reflect that some of the participants did not see themselves as carers per se. Perhaps, the carer role was a label put on them by other people around them, for example, mental health services and the wider society in order to identify their role. It is unclear whether the participants found this label helpful or unhelpful. Patrick illustrated the ongoing role of being a father.

once you're a parent, you're always a parent

He highlighted that one never stopped being a parent, no matter the circumstances or how old your child was. Curiously by using the phrase "parent", he communicated that this was the role he had undertaken, rather than being a carer. By being a parent there was a sense that the caring role required for this would never end in his lifetime – it was an enduring role. Despite there being an overlap in the roles, it seemed there was some understanding and acceptance of the commitment involved in being a parent but not in being a carer as highlighted by Ron below.

it's not something that I would have ever wanted to do. Certainly, I never had any ambition to be a carer

For Ron, there was a disconnect between being a parent and carer. He was a father - he had never chosen to be a carer or thought he would have to look after and support his son in the way he did.

#### **4.1.2 As a father, you would do anything for your child.**

Participants spoke of their unconditional love and support no matter what the situation, commenting that there was no end to what they would do for their child,

regardless of the psychosis. Alongside this, participants reported being prepared for challenges along the way in being a father.

they're always going to be your children and therefore, you feel that if any of them had any problems, no matter what it was, whether it was financial or emotional or whatever, you'd be there for them and try and help them (Leo)

because I'm his father, I want to try and help him as much as I can...If he needs help or wants guidance or like we've got to take him to hospital, then I will do that (Bryan)

Paul acknowledged the time commitment and financial cost associated with being a paternal carer.

obviously, it consumes a lot of time and expenses in terms of doing things, moving around trying to help him do things, but we just did it because we're his parents.

The term "consumes" evoked a sense of an all-encompassing, even overwhelming nature to caring, almost having a devouring quality. In line with this, Victor spoke of his daughter being his and his wife's responsibility, even though she had been in a long-term hospital for a number of years. This suggested that, for Victor, being a father required the ability to nurture and nourish.

ultimately I see it's my responsibility, we're Prue's parents

The sense of responsibility ensured the fathers kept on parenting, an experience of which was echoed by Patrick.

...just made me more determined to make sure that not only I was aware of all the responsibilities that I had, but to do what I can to make sure that that responsibility was catered for, that I can meet everything that was required

His determination to meet his paternal duties was driven by his own personal experiences of coming from a broken family, where perhaps he may have not had the nurturance he needed. This may have given rise to a consequent desire to nurture, emphasised in the quote below when he talked about responsibility being “catered” for. The word catered evoked a feeding and nourishing quality. This drove his commitment to see that his “children would’ve had all that they needed in life”.

It’s just me as a person, it hasn’t been anything that I’ve got from services... it’s just my inner strength and my determination to ensure that Jo can develop to be the person that he wants to be. That’s purely by my parental instincts. (Patrick)

This highlighted the concept of a parental instinct referred to later (in sections 4.2.3 and 4.5.3). Some participants expressed that as part of this instinct, they knew their child in a way that nobody else did or could and they used this in their caring role.

#### **4.1.3. Being a parent can hinder the caring role as you are too emotionally close.**

This subordinate theme acknowledged the difficulties of the father-child bond expressed by some participants.

you haven't got that detachment because they are your child, you treat them like a child (laughs) I'm sure as a health professional, you would treat somebody else differently than someone as part of your own family, so I suppose there is a bit of a hindrance there, because you haven't got that detachment and you always got that family bond, it's always going to be there. (Leo)

Leo's laugh in the above comment may have related to the double meaning of 'child' in this context. His repetition of the word "detachment" suggested that he felt he was never able to take a break from being a father, as it was this role that made him a parent and see his adult son as a child. Perhaps, at times, he would have liked to 'detach' himself and consider different perspectives taking an objective view on the situation or with decisions that needed to be made. In this way, his role as a father was a "hindrance", and the inability to gain distance from the child he cared for may have impacted on the quality of the care he was able to provide, and how well he was able to support his child. At the same time, Leo spoke of the benefit of the parental role:

you know their history, you know some of the things they've done and some of the things that they've struggled with, you're able to help them to direct them in certain ways where maybe other people can't.

This appeared to conflict with his earlier and later comments about “detachment” and indicated that he saw some value in his position as a paternal carer. Nonetheless, Paul’s thoughts echoed Leo’s earlier comments in being “too close”, even though he reported only feeling close to only one of his step-sons with psychosis. This highlighted the strong bond that existed between father and child, whereby even if they did not feel emotionally close to their child, it was very difficult, if not impossible, to detach their emotions from them. There was a sense that these emotions clouded their judgement because the basis of the relationship with their child was an emotional one.

I think it hinders you because you’re too close.

Leo talked about the closeness and proximity of the father-child relationship interfering in caring, or having to make big decisions for his son. Being a paternal carer had an emotional impact that would not be an issue for paid carers, highlighted by the worry that Leo experienced, and the repetition of the words “family bond” in the following and his earlier comment.

you wouldn’t lie awake at night...if it was a third party. You’re always thinking about their future and thinking how are they going to cope when they get better or if they get better () so there’s always that thought that you probably wouldn’t have if it was somebody that you saw, your neighbour or a friend, because they have their own support network () I don’t think we would worry so much if we didn’t have that family bond.

Leo's repetition of the word "always" hinted at the enduring nature of being a paternal carer. There was also a possible link to participants valuing and needing the involvement of mental health services in providing balanced and objective perspectives. This will be discussed later (in section 4.5.1).

This theme reflected the complexities of being a paternal carer where being a father may help the caring role, as they knew them better than any mental health professional could. However, at the same time, it could be a hindrance due to the inability to take a step back.

## **4.2 Change in quality of relationship with child**

This superordinate theme aimed to capture participants' experience of the psychosis changing the relationship with their child with psychosis. Many described their relationship going from an emotionally close relationship to a distant one, and vice versa, as well as it fluctuating between the two, depending on their child's mental health state, whether they were in hospital or taking drugs. Many participants strongly desired to maintain a close relationship with their child and there was a sense of them being saddened by the change in relationship, if they were no longer close. There were also references to the impact on the relationships with participants' other children, who they said felt envious of the time and attention given to their sibling with psychosis.

### **4.2.1 For better or worse.**

This subordinate theme reflected the nuances in the changing nature of participants' relationships with their children, as well as the instability in the proximity of the father-child relationship. Ron expressed this, with reference to when his son first became unwell with psychosis, which was echoed by other participants.

...over that period of time, my relationship with him changed.

Paul described experiencing both extremes of the change with his step-sons, who both developed psychosis.

It's a sort of bittersweet really. ( ) sometimes...I'm really close to him, emotionally we're quite close and so on. There are other times where I feel as though I don't recognise him at all, ( ) you feel quite distant. So it's very extreme to be honest.

There was a sense of feeling sad that he could not remain close to Tim after he became unwell. Perhaps, he felt their already close relationship would help in Tim's recovery. The "bittersweet" feeling Paul mentioned was echoed by Neil, who alluded to the extreme nature of the father-child relationship when psychosis comes into picture. It seemed from Neil's experience that the closeness of the relationship fluctuated and depended on several factors, for example, their child's mental health state, whether they were in hospital or taking drugs. This was highlighted by Victor, who described his relationship with his daughter Prue as remaining close, despite the psychosis. He acknowledged that:

it is not by any shape or form a normal family relationship

This reflected the context of the relationship as she had been in an inpatient hospital for five years. So even though they were emotionally close, they were not physically close. Victor's use of the word "normal" referred to the conventional father-daughter relationship, encompassing his initial hopes for Prue regarding getting a job, being independent, possibly married and having a family of her own. This will be discussed further (in section 4.4.4). In comparison, Patrick spoke of his

dissatisfaction in the relationship with his son, which seemed to stem from the expectations he had of the type of relationship he expected and wanted with his son.

( ) but the relationship is not as good as it was or even as good as it should be.

This may have been made more difficult for Patrick as he had recently rekindled the relationship with his estranged son from another partner, which made him realise what he was missing out on with Jo. Leo commented:

It's strong but not for the right reasons I think (laughs). It's strong in that, he is dependent on us, but not because we sort of go off and do things together ( ) some people, they go to the pub or they go to the football together and things like that, but it's something that I can't really see happening

Despite describing a strong relationship with his son, Leo felt it was for the wrong reasons. This comment highlighted his struggle with the "dependant relationship", which may be due to the expectations he had for his son. This links in with Victor's earlier use of the word "normal" referring to the usual trajectory that adult children follow in developing and growing towards independence. Again, Leo's laugh echoed an almost embarrassed quality, as this was not happening for his son which potentially caused him to question his parenting ability. Leo's use of language suggested he may on some level resent the "psychosis" as it had forced him into a position where he had to do the most basic of things for his son, with no feasible end in sight.

I treat him more like a child now than an adult () I find it difficult to talk to him like an adult because I'm having to say, "Wyatt have you done this? Wyatt have you done that?" And it's upsetting because I'd like to treat him as an adult like I do with the other two, but it is difficult...So I feel like I'm on his back all the time which is unfortunate... Horrible. I don't like it.

The use of the words "unfortunate" and "horrible", suggested the caring and dependence created came at a high cost, felt burdensome and that there were no winners, just the need to keep loving and supporting his son. It could also be "unfortunate" for his son that this level of care was needed and that he could not function more independently. Leo may have found that he had to be this way in order to avoid a relapse, as indicated by his past experiences of caring for his son. In contrast, he said:

we got a granddaughter...she just turned one...she spends the night with us here [once a week]...we really enjoy having her, and that's the highlight of the week really, so we don't feel like that's a chore, it's enjoyable

Curiously, Leo spoke of how much he enjoyed looking after his granddaughter. In theory looking after a baby can be harder work than looking after an adult, with very high levels of dependency on the caregiver and requiring a great deal of physical input. Despite this, he appeared to find it easier to look after a baby, possibly highlighting how burdensome caring an adult child can be. Further, it seemed far more complex caring for an adult child, and perhaps it did not have the

hope attached to caring for a baby who had their whole life ahead of them. Again, this may link with the expectations around what care needed to be provided depending on a person's life stage, consequently making caring for his adult son emotionally more demanding. As such, it was possible caring for Wyatt reminded Leo of how helpless and powerless he was as a father, no matter how much he did for his son. This helpless feeling was evident in all participant interviews, and is explored in more detail later as a subordinate theme (in section 4.4.1).

#### **4.2.2 Protecting child vs. looking after self.**

Four participants expressed a sense of wanting to protect their child in all circumstances, even if at times it put their own self or wellbeing at risk. Perhaps, this was what makes being a father and protecting their child so difficult, in that their child always came first but perhaps to their own detriment in the context of unpredictable and unsafe behaviour. Patrick spoke of "putting himself in danger" as well as other family members when his son was living with him.

he came into a room while I was sitting down, and punched me in the face and just run off...another time he had a knife and his grandfather was just coming to the house and he actually went out and called the police...they came down and arrested him although I told them that he had a mental health [problem]. Just seeing that happen was particularly difficult for me because at that time, I was not only trying to do whatever I can to support myself, with my disability () I was told because he was getting physical, that he shouldn't live here

Patrick's experience reflected the very real risks of potential physical harm to parents in caring for their child with psychosis, as well as their struggle in coming to terms with this. Despite the risk to himself, Patrick was reluctant for his son to leave, possibly because he felt a sense of failure as a father and a carer. It could have been more about wanting to care for his son despite the risks, as he knew it was not driven by the same intent that other violent acts by other people might be driven by.

I knew long before it actually happened, but as a parent, you try to do all you can but when he got physical, I just had to look [after] my own personal safety.

Patrick's words hinted at some sort of 'felt sense', possibly a paternal instinct that he had in relation to his son. This is mentioned in other sections (4.1.2 and 4.5.3). The above comment alluded to a self-sacrificing aspect in Patrick's view of being a father. This reflected the "huge dichotomy" that existed in looking after himself as a person/parent and protecting his child. Paul also spoke of protecting his youngest step-son from trying to harm other people, however, appeared to struggle less with this concept than Patrick did. At the same time, Paul talked about his helplessness in struggling to protect his other step-son, in the context of him wanting to end his life. This led to him witnessing his step-son being sectioned to keep him safe, which was a very difficult experience for Paul.

You can protect the youngest child, you know that he would possibly hurt someone else, and you can do something about that, so you can sort of protect other people from him and that sort of thing, but when someone wants to commit suicide, there's just nothing- you just feel like there's nothing you can do.

Paul's comment evoked a sense of (lack of) control, in that when a child becomes an adult, there the parent becomes less able to help. There were different types of risk that Paul talked about. There were risks to others which was external and where fathers could have more control. There was also the risk to self, with regards to suicide, which was internal and it seemed as if parents and other people were less able to control this. Victor talked about an experience in line with Paul's, where his daughter had been in a long-stay hospital for many years due to her level of risk. He described his experience of the hospital being like a "prison" and wanting his daughter to be home, so she could have some quality of life and be with the family. However, this had been problematic as he and his wife had the difficult time of admitting that they could not look after their daughter at home.

...she's sectioned primarily for her own safety () there's been a whole host of incidents where she would've taken her own life...Prue if she was out of there would be on a train track jumping off the local bridge within five minutes.

This links to the risk to self as described by Paul, highlighting that Prue's risk is internally driven and Victor had little control in being able to manage this. Whilst Victor considered the quality of life for his daughter, his focus was on life saving due to the risk posed by suicide. For Ron this was less evident.

I don't think it's fair on him to have that burden hanging over him. I think if he felt he could, he would go. And I don't think I want to burden him with my sort of loss. I've been able to sort of manage my life in a lot of other ways. So, I wouldn't do that to him. No.

Thus, in contrast to Paul and Victor, Ron expressed his desire to protect his son on an emotional level, in not wanting to tell him that he missed spending time with him.

This theme demonstrated the different levels and ways that the participants protected their child with psychosis from emotional and physical harm, most often at an emotional and physical cost to themselves.

#### **4.2.3 Spending quality time with all your children/Shared interests are important.**

This subordinate theme reflected some participants' experiences that spending time with their child with psychosis was an important part of maintaining their bond with them and showing their child they loved them (outside of the caring role). Neil illustrated this when he said:

...we go and play golf together, which is quite good () and we can walk about and talk and so on. And we can have fun () so that's really good. I've been to events with him, been to concerts because he's into music, he was a musician as well...So we've got some shared interests, sort of like father-son type thing (chuckles) which is nice, isn't it

Neil spoke of enjoying spending quality time with his son, highlighting the importance of "shared interests". There was a sense of playfulness in the latter half of this comment, where Neil chuckled and said "father-son type thing". It allowed a glimpse into the true nature of his relationship with his son, separate from the psychosis and caring role. However, this was short-lived as it was followed by a

comment acknowledging the influence of the environment on their interaction and recognising they may be doing different activities than they previously did and the quality of their time spent together was different.

( ) we try and bond...when actually we go out and play golf together, we can actually bond a bit. Or if we go...not so much now...and it might happen again in the future because there's a band I want to go and see with him, but if I go with him to see a musical act, then we can sort of have a bit of a banter, you know, that type of thing which is nice father-son stuff. But that's about the environment, if you put us in a different environment, it's easier for us to communicate.

Thinking about the quality factor, this was referred to earlier in regards to quality of life but here it could be used in the context of the quality of a relationship or activity. The "try" and "a bit" phrases showed Neil attempts to "bond" with his son, and perhaps the change in environment enabled them to be father and son, rather than carer and child with psychosis. This resonated with Ron's experience; however, he struggled to reconnect with his son because it was too difficult for his son to manage, unlike Neil.

He and I don't tend to go out. Even after he got the psychosis, we used to go out occasionally and watch football or cricket. But, um, over the last say five years... he's found it difficult to go to football matches, um, or cricket matches...Yeah, I do [miss doing that], actually...I go with my grandson Uh, I take him occasionally. Um, so, and I would definitely take Arthur. And then, yeah, I mean, it

would be nice to take him. Um, and I would probably go more often if, you know, if the opportunity arose, um, but, uh, it doesn't

The repeated “uh” and “um” in this extract broke up the speech, highlighting just how tentative this was and possibly how difficult it was for Ron to talk about not being able to maintain the level of relationship he once had with his son. This could also be associated with the changes in shared father-son interests, as Ron described earlier in the interview. This may have left him with a feeling of not knowing how to reconnect with his son, reflected by the tentativeness in the above quote and breaks in speech.

Another struggle that some participants identified was feeling guilty for spending more time with one child than their others. Participants expressed wanting to treat their children equally, show them that they loved them and they were individually important to their fathers. Patrick reported spending more time with his previously estranged son than his son with psychosis (Jo).

Currently, I feel that I'm putting more into Alex's life than Jo's life... which is not what I would've liked, that's not the position I would like to be in but it is what it is

Although, it was understood that the change in relationship was to do with circumstances outside of Patrick's control, this comment reflected how desperate he was to be an equal father to both sons, as well as to reconnect with Jo. The other side of this struggle was elucidated by Bryan and Leo, who felt that the child with psychosis needed more help and support than their other children. However, this was in the context of their children feeling

jealous of the time they spent and continue spending caring for their child with psychosis.

she doesn't want to know us let alone Ken and has actually written us off now for five years. It's to do with the time that we spent with him or looking after him...We would still like contact with her but, we feel that we give support to those that need it at the times they need it. And right now, Ken needs it... (Bryan)

...our daughter got quite resentful because it's all about Wyatt (). I think now she's older, she's got her own daughter...she understands a lot more and she's a lot more sympathetic, but we do try our best to support or try and treat all of our children the same way. (Leo)

These quotes highlighted how hard it was for parents to be equal when their children's needs differed. However, it showed that the emotional needs of all children were the same and it was potentially this aspect, which made it hard for parents. They gave to their children at the expense of their own needs and it was only in adulthood that the other children may begin to understand this. Unfortunately for Bryan, this was not the case and caring for his son came at the cost of his relationship with his eldest daughter, which he found very "difficult". Nonetheless, he maintained that his son was his priority and deserving of the level of attention given to him. Leo spoke of trying his best to be an equal father to all three of his children and feeling that he never really achieved this. He described his youngest daughter's journey from feeling "resentful" to "sympathetic". However, there appeared to be a sense of regret of the time he missed out on in his daughter's early years, as well as

a sense of relief that she had now come to an “understanding”, perhaps relieving some of the guilt he felt.

This theme demonstrated how some participants wanted and enjoyed spending time with their children regardless of the psychosis and the associated struggles with this. All participants shared their sense of how their caring role and child's psychosis had had an impact on the wider family as well as the relationships with their other children.

### **4.3 To share or not to share**

This superordinate theme reflected the mixed experiences that participants spoke of when talking to other people about being a carer and their child with psychosis, both in carers' groups and in social contexts. Although, overall there were positive reports of attending carers' groups, some difficulties were identified. Some participants described trying to speak to friends and family members, however, they found others could not really understand the complexities of their parental caring role. This left them feeling invalidated and distant from others.

#### **4.3.1 Sharing eases isolation.**

Most participants described being able to access carers' groups, finding them beneficial and enabling them to cope in their caring role. There was a sense that the only people who could really understand participants' experiences were other parents who also have a child with psychosis and this connected them together.

...you are meeting other people who are going through the same situation, and that is the biggest thing that my partner would say, she felt so alone. We know- I know that she would probably be really ill if she hadn't had this meeting with all the other carers because, they allowed her to, like you say, laugh, joke, cry. (Paul)

it worked quite well to begin with because we had very limited knowledge about what this is all going to be about. So when we're going through a crisis sort of stage () people's experiences were particularly useful. (Neil)

Paul and Neil commented on learning from other carers through shared experiences and feelings, particularly when their child first became unwell. Neil's experience suggested that he only accessed the carers' group when his son first became unwell and in times of crisis.

...we went to quite a few carer peer support groups initially, which was quite useful, but stopped after a while. I think my wife continued going to them, I didn't, and maybe because I was busy at work or whatever. But I went to a few of them, and they were useful

From a father's perspective, Neil found it difficult to balance regularly attending the carers' group, despite finding it helpful, and other responsibilities such as work. This highlighted Neil's pragmatic nature and it was possible that other paternal carers face a similar dilemma, even though this was not openly reported by other participants. Conversely, Ron and Leo explicitly stated that they are proactively involved in supporting other carers, together with their wives. Given the focus on fathers' own experiences, the relationship between the participants and their partners in explored in a minor subtheme ('In it together') presented in Appendix 17.

I'm keen to try and sort of help other people who are going through similar experiences to the ones that we went through () which is why my wife and I are sort of involved in carers groups and so on. (Ron)

Piper has set up that carers group, because before that, there was nothing, or there didn't seem to be anything () So Piper said, "There must be more people out there, like us looking for someone to talk to...And it's amazing, we've got how many people now, probably about 10 or so people, who've all got relatives, daughters or sons with mental health issues, and we get together once a month and we can have a moan and groan basically (laughs), and it's just a self-help group if you like, but it's really useful... (Leo)

Leo's description of the carer's group was very similar to Paul's, in that it was seen as a confidential space where they could speak freely, and be themselves without fear of judgement or invalidation. Having a break, or more importantly human connections with people that understood, albeit a short one, from the child they cared for (or perhaps from the wider world), appeared to be valuable in giving the fathers space to reflect and process their feelings.

There was a contrast of fathers being able to connect with others with shared experiences and finding it more difficult with people that did not understand, which is explored below. This again related to the quality factor in relationships and understanding, which was mentioned in an earlier section (4.2.4).

### 4.3.2 Sharing is risky.

This theme related to the difficulties that participants faced in talking about their caring roles and experiences as well as the impact their child's psychosis had had on their systems as a whole. Several participants shared a sense of experiencing family and friends becoming more distant, both emotionally and physically, in general due to a lack of understanding, as described by Victor and Ron.

they have either accepted the fact that we're going to talk about it and have stayed friends or can't cope with what we're saying or maybe we just bore the pants off them () or it may actually be that they just can't mentally cope with the situations itself which we can understand and they have tended to drift away, so. (Victor)

...Members of the family for a time had difficulty coping with it.

Ginny's sister is a case in point where she and her husband...thought that sort of looking after him wasn't as big task as they found it to be. So they really struggled with that. And that caused a problem () and there was a falling out. (Ron)

This was similar to the experience described by Neil, who highlighted the difficulty he experienced in talking about having a child with psychosis, due to the lack of basic understanding and knowledge of mental health. This feeling was present for most of the participants.

it's difficult to talk about it to anybody else apart from certain people who seem to understand a bit more about it (Neil)

They all know but they don't take it on board. In fact, one of my friends turns around and said, "Why don't you turn the phone off?" Because he [his son] will get so anxious he could do anything. "Oh, well, I'd turn my phone off." That's his reaction. So when you get friends like that, who wants enemies? () there are friends, but they don't appreciate mental illness. (Bryan)

Bryan's comment illustrated just how hard and frustrating it was for him when people did not understand. It was, therefore, unsurprising that participants struggled to talk about their experiences and tell people they had a child with psychosis, when they could so easily be dismissed and invalidated by so-called "friends". In contrast, Patrick viewed it as important for people in his life to both know about and understand his caring responsibilities and son's mental health, for them to remain in his life.

Most people I know, know of Jo and I make that quite clear to them, and obviously if they don't have an understanding of what my life is because of Jo, then we don't have a friendship, but most of them do really...there aren't people who don't understand mental health, I know there are, but I don't associate myself with people of that ilk.

Patrick appeared confident in cutting links with people who were not able to understand this. This appeared to be a risky strategy as there was the chance of isolating and alienating himself in doing so. It seemed that he found it empowering

to make these decisions rather than be on the receiving end of them, as he had in the past.

Interestingly, Neil also commented on his ability to hear other carers' experiences, demonstrating his feelings that sharing experiences was not always positive and sometimes felt like a burden. He expressed a sense of it making him feel hopeless hearing difficult stories from parents who had been caring longer than him or there being little comfort in hearing similar stories and experiences of other carers, to his own. It appeared that Neil did not feel he always had the capacity to be able to listen empathically to other carers' distress, despite being a carer himself.

But I think the problem we have sometimes is that, you get the sort of selfish attitude that I've got... we've got our own problems without listening to everybody else's.

There was a sense of feeling very overwhelmed by the burden of care and the internal struggle of wanting to support others but feeling unable to due to feeling too overwhelmed. This may illustrate a sense of self-preservation that fathers experience in their caring role. It could also link to the earlier themes about the children needing to come first and highlighted another example of why it was hard for fathers to focus on their own needs as it was "selfish".

#### **4.4 Acceptance is a struggle**

This superordinate theme reflected the difficulty that fathers faced in knowing that their child has psychosis, as well as realising that they would not have the life they had envisaged for them. Participants had spent on average 15 years in their caring roles and it seemed to have taken this length of time for them to get to a place that could be called acceptance.

#### **4.4.1 A double-edged sword: Feeling helpless.**

Participants described feeling that no matter what or how much they did for their child, it was never enough and it left them feeling helpless. There was a sense that there was nothing that participants could do to cure or get rid of the psychosis or symptoms relating to their child's psychosis.

...there's nothing really you can do or say to that child that's helping in any way, it becomes so really difficult because there's nothing that you're doing to try and help the situation () but there's nothing happening, there's nothing- getting any better or...there's nothing you can do. There's nothing you can do or anything about it. It's there and that's what we got to cope with. (Paul)

Paul's repetition of the word "nothing" on six occasions emphasised the helplessness and stuckness he felt. This spoke to the lack of control that was mentioned earlier in section (4.2.3), with the sense of "nothing" that he had in his power to alter it. Despite being a step-father, he expressed more frustration than other participants. This could have been because he cared for two sons with psychosis, coupled with trying to negotiate boundaries with the sons' biological father. There was also a sense that participants were desperate to move from this 'helpless' position and expressed desires for their children to be independent so that they could function in the future. This was apparent for Bryan and Patrick, who spoke of worries about what would happen to their child when they died.

I'm really trying to push him now into being able to live as a normal human being, doing the normal, mundane things. So that he's ready to just carry on if we weren't there. He is reliant on us being there

100% of the time... I want it to stop. I want it to cease and we can't get that. And I'm trying to push for it, and it's just too difficult.

(Bryan)

I tried to give him his independence, but I'm also aware that he's not able to manage himself...It's a double-edged sword almost. (Patrick)

Both Bryan and Patrick's comment illustrated that they want to help their child in their recovery and regain their independence, whilst also having an awareness that their children struggle to manage even the most basic tasks – 'a double-edged sword'. Most participants echoed this feeling as well as the struggle of their child being reliant on them. There appeared to be internal conflicts between worrying about the future, and feeling that the dilemma posed by their child's illness, highlighted by Patrick's use of the expression "double edged sword". This links to the earlier sub-theme regarding protection, in that they as fathers felt they should be able to protect their children and fix their problems. However, with mental health they were only able to temporarily ease their child's suffering by supporting them with the emotional and practical aspects in life, emphasising the helpless nature of the paternal carer role to their adult children.

#### **4.4.2 Trying to make sense of why and how this happened to my child.**

Participants described continually attempting to understand the experience of supporting their child experiencing psychosis, but rarely feeling that they had made any real sense of it. Additionally, there was the continual sense of 'not knowing' so whilst the child became ill, fathers were desperately searching for ways to understand. This was particularly demonstrated by Leo's experience.

I don't make any sense of it. It's difficult. It's something I never come across before...[I] sort of understand a bit from my own research and things to try and make sense of it a bit more, trying to understand it a bit better than I suppose really.

His comment acknowledged the complexities in the determination for an answer against the feeling that he would probably never understand why, which was also expressed by Victor.

everybody's brain is totally different, everybody reacts to the things in a different way and Prue, the wiring in her brain for whatever reason it is, is given her the life that it's given her and so...that's how we rationalise it, yes, I mean it is just an extremely unfortunate set of circumstances that actually I don't think anybody could have done anything differently, throughout her life to avoid happening.

Victor appeared to attempt to communicate the sense he had made of his daughter's psychosis. Ron described coming to a similar explanation:

I mean, what I now understand, rightly or wrongly, is that sort of the opportunity to develop schizophrenia probably dwells in a lot of us () but it needs often a trigger to set it off.

However, Ron's sense-making seemed tentative as he questioned the accuracy of his understanding. For Bryan, fighting the psychosis did not allow him to consider that his son may have an illness and this impacted on how he interacted with him. There was a contrast here, where some participants spoke of a lack of

understanding and not knowing, with Bryan attributing his son's psychosis to other reasons, as described below:

For many years I just thought it was pure drugs. I thought he was just taking drugs, drugs and drugs and it was not an illness. I couldn't get it in my mind that he still had a problem other than just the drugs. I couldn't accept it...I wouldn't accept it. () it's only in the last few years that I've accepted that he has an illness that causes problems with him...It's me accepting the fact that he has a problem and it's not just the drugs.

The repetition of the word "drugs" highlighted how convinced Bryan was that this was the cause of his son's problems. Bryan's use of the words "couldn't" and "wouldn't" was interesting, as it suggested that the barriers to understanding were internal. His initial explanation provided more hope for a solution and treatment, perhaps giving him more of a sense of control, linking back to the theme of control mentioned earlier in sections 4.2.3 and 4.4.1. It was also more socially acceptable to have difficulties with drugs and recover from them than to have a mental health problem, particularly in the context of psychosis which was less understood whilst also carrying more stigma. Therefore, Bryan may have felt less of a failure as a father and less judged by others, in believing that it was "drugs" that was the problem. Further, perhaps coming to an understanding that his son had a mental health problem, allowed him to let go of the anger he felt towards his son and take a different position. In that, he could be patient and empathic towards his son and the difficulties he was experiencing. For Bryan, acceptance of the psychosis enabled him to be more compassionate and understanding to his son's suffering.

This theme highlighted participants' struggles with trying to figure out why their child in particular, had developed psychosis and the process of accepting this. Even though, they had come up with tentative reasons, which appeared to help them with the process of accepting their child's illness; most participants seemed in conflict with this and the sense that they did not know why it had happened to their child. The fathers' wants for their children seemed in conflict with the losses that they had had to accept, thus, the route to acceptance may not have been a straightforward or easy one. This will now be explored in the following theme.

#### **4.4.3 Hope vs. Loss.**

All participants spoke of their expectations and hopes for their child with psychosis and going through the process of accepting that they would probably never be the adults they had hoped.

...obviously I was very disappointed that he couldn't do what other normal boys would do and that disappointment was really tremendous for me. (Bryan)

there's times where you just want to cry because you feel bereaved, a bit selfishly I suppose, your expectations have gone out of the window and he's not really going to have much of a life (Neil)

Bryan's use of the word "tremendous" illustrated the emotional impact of the disappointment and realisation that his expectations for his son would never be fulfilled. This emotional impact was also reflected in Neil's experience when he said "just want to cry", which is echoed in a later comment where he expressed frustration and feeling down.

we had hopes of him getting a degree, getting a job...we had sort of ambitions for him () it certainly took me a while to realise that my ambitions for him were really just not going to happen. (Ron)

Ron referred to the length of time it took to realise the implications of his son's psychosis on his life and future. Interestingly, Leo described being scared of having hope, in case once again his hopes were dashed by the psychosis.

You think, is there a light at the end of the tunnel... is it going to get better?

Similar feelings were described by Neil and Ron, who spoke of a "miracle" and "cure", as if their sons getting better and having the life that they envisaged for them was beyond the realms of reality.

expectations have been dashed because as a father... maybe it's a gender thing, but you probably have high expectations () But as a father...what you planned for is them to grow up, get married possibly, have a partner anyway, possibly have children, have a house, et cetera. So that isn't going to happen...you don't sort of give up on hope completely, but you do feel a bit frustrated and...it does get quite depressing sometimes. (Neil)

a period of 10 years when he didn't have any acute crisis. () he became quite well...there is a positive side to that in the sense that he still has that ambition to be better. But I think in truth, unless there was a medication that would suddenly come over the horizon

and be available to him that would actually cure him, nothing will change. (Ron)

Neil expressed that he still had some hope that things would get better for his son but acknowledged that his expectations had changed since his son became unwell. Ron talked of the push-pull relationship he had with hope though perhaps more for those coming into the system.

We're hopeful, I mean, not so much for Arthur, really...but for people going into the system for the first time now, I think the approach is much better.

Perhaps, Ron envisaged a better experience, quality of life and level of recovery for others compared to what his son had had, and this seemed rooted in improvements in understanding and care provision. Victor spoke of a similar loss, albeit from a slightly different position and point of view than the other participants, as his daughter nearly died due to negligence on the part of medical professionals. This experience led him and his wife to come to a very painful acceptance.

in all honesty [we] have come to the conclusion that the quality of Prue's life is so poor and has been and the prognosis and the outlook is so poor that she will be better off if she passed away than being alive...in terms of quality life, as I said before her quality of life is zero, absolutely zero

Victor's repetition of the words "quality of life" and "zero" coupled with the phrase "absolutely" reflect how important these things were to him as Prue's father

and the tragedy for him that she did not have this. It was as if, on some level, he could tolerate his daughter being in long-stay hospital, if he could be reassured in knowing that she had a reasonable quality of life. The painful conclusion that she did not highlighted his difficulty in maintaining hope for Prue and her future, as well as his faith in the mental health system and medical professionals. This will be explored in more detail in the next section (4.5).

This theme reflected participants' grief for the loss of the life that their children could have had, had it not been for the psychosis, as well as their re-evaluated hopes for their child's future.

#### **4.5 Mental health services: Inconsistency vs. luck**

This superordinate theme was present for all participants describing mixed experiences of mental health services, which had a huge impact on them and their child. The extremes of their experiences ranged from thorough, consistent and genuine to neglectful, disappointing and potentially harmful care. Neither extreme could be predicted from the outset, perhaps reflecting an element of luck in the type of service the participants' children received.

##### **4.5.1 When services get it right, it can be life-changing for child and family.**

Simon was the luckiest... I can't say lucky. When he became ill, they had the early intervention team and without their help, I don't think he would be where he is... Tim's completely different in the way he was cared for.

Paul's step-sons had different experiences, highlight that early intervention was crucial to outcomes. Paul spoke very highly of services and in essence, said that they saved Simon's life. Similar sentiments were echoed by Leo and Neil.

The staff there were very, very good, they were excellent, and because we live such a long, long way away, they were quite sympathetic for us when we went to visit, instead of sticking to the rigid visit hours, they were quite relaxed about it...a chap used to come out and go running with him and take him out to places, it was really, really supportive, and they supported us as well. () he had his own therapist, and there was also a therapist assigned to us and the family, and he'd ring us up or we'd go and see him - he was very, very good. Very good. Very well supported it was (Leo)

We've been to appointments; we've been quite proactive like that. We established a quite good relationship with the psychiatrist, arranged with Daniel's consent to have some shared time with the psychiatrist about his recovery... either with Daniel there or not there...In the very early stages of his illness, we had family intervention therapy, which is quite intense, which was good. And that actually helped a lot. I mean that sort of helped stabilise things a bit, and got a few things out in the open... Yeah, me and my wife, Daniel, and there were two facilitators from, I think from the team and they were very good. (Neil)

Leo's satisfaction with services was conveyed by his repeated use and double repetitions of the words "very, very" and "really, really". He valued the separate support that was available to him and his wife, which must have helped them make sense of what happened to his son when admitted as an inpatient. Being included in their child's care was also valued by Neil, as well as being offered support at the "early stages" of their son's psychosis. Treatment involving family helped everyone make sense of the psychosis and, in turn, the way in which parents supported their child. This was echoed in Paul's earlier comment, regarding the input of the early intervention team and was also described by Bryan.

And we were extremely lucky, it was the first episode psychosis team. And they took him under their wing for two years. And in that two years they did absolutely everything for him, it was fantastic. But at the end of two years it's time's up. You've got to go into somewhere else and it just failed after that.

Despite Bryan having an initially similar experience to most of the other participants, he talked of this changing dramatically once his son was a few years into the illness, illustrated by his use of the word "failed". This sense of failure was also highlighted by Paul:

The early intervention team, it was the same nurse, same person, and they were there every time you needed them. Whereas [with Tim] you got a child that's trying to commit suicide and then you got to take him to the A&E, and sit there for four and a half hours, and then when you explain that my child has just tried to commit suicide...they turn around and say, "well, I think he's perfectly okay

now and you can let him back home.” It’s not really what you want to hear, you want for that child to be taken into care and looked after so he can’t hurt himself.

This mirrors the lack of understanding mentioned earlier in section 4.3 but in the context of health services, emphasised by the completely opposite approaches to his step-sons, experienced by Paul. His frustration was evident in how he described his experience at A&E, probably compounded by his intense worry for Tim’s safety and not knowing what to do to keep him safe. It was in stark contrast to the consistent and supportive experience he had with his younger step-son, which was mentioned in his earlier comment.

This theme highlighted that participants felt consistency of mental health services and being included in care planning were key aspects in their child’s recovery. Lack of continuity and communication were identified as factors that hindered the above.

#### **4.5.2 Services supporting child support parents.**

This theme highlighted the expectations and experiences of some participants. They expressed that they just wanted services to appropriately support their child, which in turn supported them as parents. This was highlighted by Patrick, when he said:

Services have helped me as a carer ( ) if they want to help me, they would help Jo. But ultimately, my feeling is that, everything needed to be on Jo because as a carer, I think we only go to services or support for our self if we need it...I think [knowing he is supported] would give me peace of mind

Patrick wanting “peace of mind” illustrated his constant worry about his son being safe and supported, and what he really needed was for services’ support to be directed towards his son. His worry was possibly emphasised by the fact he was limited in what he could do for his son, due to the physical risk issues. Patrick’s comment also highlighted his selflessness as a father. Despite, living with his own long-standing disability and distant relationship with his son, he did not want any help for himself directly.

Currently the situation is not as I’d like it to be, I am going to try and change that, but I feel without support of services, going forward, given that what they have been in the past, it’s going to be very difficult

Patrick’s determination to make things better for his son, tied in with the earlier idea of children always coming first and fathers viewing considering their own needs as “selfish” (in section 4.3.2). He acknowledged the need for services to support his son, but there was an element of hopelessness for his son’s future and recovery when he said “it’s going to be very difficult”. A similar feeling was echoed by Bryan.

They have got to step up the game in supporting Ken so that he doesn’t have to have the contact with us all the while.

There was a sense here that Bryan felt burdened and overwhelmed by the numerous daily phone calls that his son made to him and his wife, involving hours a day on the phone. He expressed feeling dissatisfied with the current level of care his son was receiving, in that if it was enough, he would not receive so many phone

calls. This may also be a way for Bryan to enforce some boundaries with Ken, which he felt would be supported by Ken having professionals to speak to about his concerns.

Even though support for carers was helpful, paternal carers highlighted that their primary concern was for their child to be appropriately supported and cared for, which unfortunately was not the reality. The greatest support they could get was knowing their child was supported and in order to facilitate this, fathers' had to take a proactive role.

#### **4.5.3 We need to advocate for our child to get the help they need.**

This final subordinate theme captured how participants interacted with mental health services and other related systems on behalf of their child with psychosis.

I have complained bitterly () I complained that no one had gone to see him or been in touch with him for three weeks. I specifically stated that the CPN should've been there...Following day, the woman phoned Ken up and said, "Your parents have complained about me so I've got to come and see you." Really, why didn't she go and see him off her own back? Why do I have to complain to get that?

Bryan's experience of "*complaining*" appeared to have left him feeling annoyed and "bitter". His exasperation was reflected by the two very direct questions at the end of his comment, which were legitimate questions. This frustration was probably compounded by a worry that his son might feel that he was only seen by his CPN because of the "complaint", rather than because services actually cared about his well-being. Neil and Leo described pushing to be involved in their child's

care, with the on-going complication mentioned by other participants, that as their child was technically an adult, confidentiality became an issue.

Including us is good, it is a positive thing. We had to sort of negotiate to get more information about what's going on. Because obviously he was a young adult, so we had to sort of push for that all the time, that's quite energy intensive...because we manage to articulate well and we were prepared to support Daniel, and it clearly takes the pressure off services if we're supporting him. (Neil)

we'd say to the care coordinator, can we have quarter an hour with you as well, so we could actually talk to the professional as well, and sometimes we'd all meet together with Wyatt's permission, we'd all have a chat together, so that was good. (Leo)

Interestingly, Leo's experience was positive, compared to Bryan's and Neil's. This might be because the professionals and his son were amenable and open to Leo and his wife being in the loop, whereas Neil and Bryan had to "push...all the time" for it. This might have enabled him to advocate for his son in a more gentle and planned way, rather than after-the-fact as both Neil and Bryan experienced. Neil commented on the time, "energy" and negotiation involved, which was probably true for participants across the board. Victor spoke of continuously asking questions to the inpatient staff and professionals who cared for his daughter, who he clearly stated was unable to advocate for herself and her care. There appeared to be a contradiction here, as there was a push to care for carers as the role was demanding

and intensive, yet participants described the above experiences as draining their energy and resources.

...I ask the question Why are we doing this? What are we looking to achieve? What we're doing is just in a holding pen that's seen as about... What is the ultimate aim here?

This felt like an extreme endpoint, however there was a sense that this final question said it all. This could be seen as challenging, albeit gently, however this was in the context of his daughter nearly dying due to negligence on the part of professionals, as well as Victor feeling that his daughter had no quality of life.

This theme highlighted how participants had to step in, as their children were not in a position to advocate for themselves. Rather than paternal carers having to constantly chase and follow up mental health services, there was a sense that this process should be intuitive. This was because intuition or the 'felt sense' that was mentioned earlier, is embedded in the parental role; specifically for the participants in this study it could be referred to as paternal instinct. Further, this process should not only be embedded in caring for people with psychosis, but also in the interactions that professionals have with parental carers.

The next section (Discussion; chapter 5) provides a summary of the findings.

## **CHAPTER 5. DISCUSSION**

### **5.1 Overview**

In this final chapter, I have returned to the research question and presented a summary of the results. This is followed by a discussion of the results, regarding their relevance in relation to existing research findings and psychological models. New literature not previously mentioned has been included, in line with the IPA methodology allowing for new findings to emerge. I have then considered the key implications for clinical practice, followed by reflections on the strengths and limitations of the study. I have also offered recommendations and suggestions for future research. Finally, I have ended with personal reflections and a concluding summary of this research project.

### **5.2 Return to the research question**

This study aimed to address the research question:

What are the experiences of fathers caring for an adult child with psychosis?

### **5.3 Summary of Results**

Five superordinate themes emerged, which included fourteen subordinate themes. Participants spoke of a range of similar and different experiences, reflecting the various ways in which they navigated their caring roles, the tensions in being a paternal carer, and relationship with mental health services. As it is outside the scope of this thesis to discuss each subordinate theme in detail, where possible and appropriate, themes have been synthesised.

### **5.4 The tensions in being a paternal carer**

Being a father was seen both positively and negatively due to the emotional connection with their child. Participants expressed that they would do anything for their son or daughter and ultimately saw themselves as responsible for their child.

This could have been because of the love and responsibility they felt towards their son or daughter, giving meaning to both their fathering and caring role (McAuliffe et al., 2014). Fraser and Warr (2009) explored issues for men caring for family members with 'mental illness' and found that fathers in the sample never questioned the on-going care or responsibility of their child, in line with the current study. It could be understood as fathers wanting to maintain and uphold the crucial parts of their connection with their child and so extend the characteristic duties and responsibilities associated with parenting (Fraser & Warr, 2009). This links with the moral assumptions in how fathers feel they should act and potentially how people in their social network or community will view their actions (Wall & Arnold, 2007). This is in the context of the shift in the culture of fatherhood over the last 30 years, from the colonial father to the father as a co-parent, who takes on more caring responsibilities (Cabrera et al., 2000). As caring is often seen as a feminine practice, it is important to discuss this in relation to masculinity (Doucet, 2004). It has been argued by some that fathering caring practices fall into the hegemonic form of masculinity, which incorporates qualities of "being strong, successful, capable, reliable, in control" (Kimmel, 1994, p.125). However, it has been questioned whether fathers and caring come under subordinated masculinity (expressing qualities opposite to hegemonic masculinity, e.g. being overly emotional or acting in a feminine way) or complicit masculinity (not fitting all the characteristics of hegemonic masculinity but not challenging it either) (Doucet, 2004). Cabrera et al. (2000) suggest that new theoretical models of parenting need to be formulated to include and understand the shifts in family structures, notions of what it means to be a father across cultures and in relation to masculinity.

*Reflecting on my experience meeting and speaking to the fathers, I was really struck by the dedication, strength and unwavering resolution they had to support their children, in the context of such difficult circumstances. I found myself wondering how anyone could doubt how much fathers care or their involvement in caring.*

Despite an overall sense of experiencing carers groups as helpful, not all participants attended these support groups regularly participants and reported being the only male carer in the group. A practical reason for this might be fathers' discomfort at attending a group that mainly mothers go too (Fraser & Warr, 2009; Spandler et al., 2013). Furthermore, this also links with research showing that men generally struggle to express their emotions at the best of times (Spandler et al., 2013). In particular, they find it difficult speaking in groups, to females and in clinical settings, due to feeling stigmatised and feminised. This is discussed further in the clinical implications (section 5.7.4) in considering how men can be engaged in therapeutic interventions. As mentioned earlier, there has been an evolution of the fathering role which has been perpetuated by a higher number of mothers remaining in the workforce, earning salaries relative to their partners and flexible working (Doucet, 2004; Wall & Arnold, 2007; Rochlen et al., 2010). However, all but one of the fathers in the current study identified themselves as the main breadwinners (refer to Section 3.4.8) in their families and so may not have been able to attend at the times that the carers' groups were occurring. Wall & Arnold (2007) highlighted that despite the recent changes in how caregiving in carried out between parents, mothers still take overall responsibility for caregiving fitting with societal expectations. They suggested that this associated with the traditional cultural

understandings of motherhood and fatherhood, as well as the shortcomings in government policy, workplace culture and the gender pay gap.

Research shows that social support is key in reducing carers' distress, as well as promoting helpful ways to cope (Joyce et al., 2003; Magliano et al., 2003). However, carers' access to their social network and support is drastically impacted by the stigma and shame linked to the psychosis-related diagnosis (Magliano et al., 2005; Gutierrez-Maldonado et al., 2005). This explains the experiences of invalidation and not being understood that emerged from the participants in this study. This can lead to fathers feeling isolated and actively withdrawing, due to being unable to speak to other people about their feelings related to the caring role, amplified by the inconsistency of mental health services. Recent research suggests that carers of people with psychosis are around 10 times more isolated than non-carers. Moreover, they are significantly more isolated compared to carers supporting people with other health difficulties (Hayes et al., 2015; Magliano et al., 2005; Perlick et al., 2005).

As these carers do not have a space where they can process and make sense of their emotions, it could have a negative impact on their own mental health, physical health and ability to support their family. Additionally, many people (which most likely includes a high proportion of fathers) do not identify themselves as a 'carer', and so they may not seek carers' support forums or resources for themselves. As such, it may be a long time, possibly even years before they become aware these types of groups or services exist and may be beneficial, particularly if they are not signposted to them by services. Moreover, they may be less likely to seek out further support, if they have felt dismissed or overlooked by mental health services (Onwumere et al., 2016).

### **5.5 The enduring nature of caring**

The enduring nature of the psychosis appeared to have parallels with the enduring nature of caring, as even when participants were not physically close to their child, they were never far from their minds. Participants reported feeling upset by the change in relationship, possibly reflecting the importance to them of having a close relationship with their child. Further, one participant appeared to be devastated that he was no longer able to live with his son, due the incidents and on-going risks of violence towards him, despite enduring this for a long time before his son moved out. This fits with current research showing that carers want to protect their relative from the potential consequences of their psychosis-related violence, as well as minimising their own needs and concerns for their personal safety (Lavis et al., 2015; Ferriter & Huband, 2003). Research in this area shows that 52% of carers of people for psychosis have reported 'patient-initiated violence' (Chan, 2008). Onwumere et al. (2018) explored the experience of violence in first-episode psychosis caregiving relationships and found that there was a lack of predictability over when the violence occurred with participants reported feeling scared and fearful yet wanting to stay safe. Moreover, incidents of violence generally occurred at the carers' homes, when no one else was around. This highlighted that although incidents of violence were not directly asked about in the current study, and only one participant spoke of it, it was possible that other participants had also experienced violence from their child.

Participants expressed an enduring sense of helplessness, no matter what they had done or were doing to support their child, whilst also trying to maintain some form of hope for the future. This may be compounded by the on-going uncertainty and questions relating to whether their child will ever be able to regain and maintain independence. Despite the length of time that participants had been in

their caring role, they still struggled to make sense of their child's psychosis. Making sense of the psychosis may be important for participants as it helped them to feel more in control of the illness and less stressed (Onwumere et al., 2008). Additionally, Addington et al. (2003) found that caregivers' emotional well-being was linked to their appraisal of the care recipients' illness, as well as the input from mental health services.

### **5.6 Relationship between services and paternal carers**

Participants described their experiences of caring being dependent on, and impacted by, mental health services, with little predictability regarding which level of service they would receive. When services were consistent, person-centred and involving the family in the service users' care, participants were able to feel confident in their caring role, make sense of what was happening to their child and felt hopeful about the future. However, when services were irregular in their contact, did not communicate effectively or include the family, participants reported feeling stressed, overwhelmed and frustrated. They reported feeling disappointed with services and losing faith in the mental health system. Even though some participants acknowledged the value of being offered support in their own right (for example, a carer's assessment), they expressed wishes for these efforts to be put into supporting their child. In this way, knowing their child was well supported was an indirect way of carers being supported by services giving them peace of mind, fitting with Askey et al.'s (2009) paper, which focussed on what carers needed from mental health services.

In order to get their child's needs met, a few participants expressed they had to be proactive and advocate for their child, even complaining and threatening to take issues to senior managers. A similar theme was found by McCann et al.

(2011b), where parents spoke of the importance of assertiveness to access services and implement plans to support their child. However, being assertive and complaining may make the involved professionals resentful towards parents and their child resulting in avoiding them, which may reinforce the notion that parents must be assertive for their child's needs to be met.

## **5.7 Clinical implications**

The clinical implications of the findings from this study can be considered on multiple levels; service, community, family and individual level. Therefore, this section will be discussed according to these layers.

### **5.7.1 Service-level implications.**

When including carers in interventions, services can consider how they include fathers. For example, family interventions are generally offered in clinic or outpatients during working hours, Mondays to Fridays. Generally, fathers have to continue working as they are the higher-income earners, especially in the context where mothers reduce their working hours or give up working to support their child. Therefore, these interventions are not accessible to fathers and may exclude the rest of the family from receiving this therapy or limit the benefits of it when the whole family cannot be present. Perhaps services can be more flexible time wise in offering these interventions, for example, seeing families out of hours and/or at their home.

A current narrative in services is around the gender imbalance in caring (as alluded to earlier in this thesis) in that it is always mothers who are more invested in the well-being of their child and involved in their child's care. However, this study highlights the commitment of fathers, as mental health professionals are not always aware of the closest people to the service user. One way of changing this narrative, could be by asking service users more specifically and in more detail about the

people in their family or system and who supports them. If fathers can be involved more explicitly at the start, it may change how fathers interact with services and the perspectives that mental health professionals have of them.

A repeated theme emerging from the interviews is the consistency of mental health services. Staff and service managers could be more mindful of the impact of small changes on families and do more to scaffold these changes through how they are communicated, thus, making it easier for families to tolerate and manage. Furthermore, participants in the study suggest that care coordinators should have regular, fixed contact with their child, rather than parents chasing this up or, in some cases, complaining. In line with the participants commenting that services supporting their child actually supports them as carers, they suggest that housing is a key part to this. Many participants commented on the inappropriateness of the accommodations in meeting the needs of their child, leaving them to worry as parents, and having to step in to plug the gap.

As participants in the study suggest another area for improvement in services is psycho-education and availability of information, not just at the start of the psychosis but as the illness progresses. This would reflect the different levels of support and information needed by fathers at different points in their caring roles (Kuipers et al., 2010).

On a primary care level, general practitioners (GPs) also have an important role to play given their role as gatekeepers to mental health services. They are potentially the biggest source of professional, individual support for carers. This can be done by putting alerts on the service users' and carers' record as a reminder to ask about the carers' health needs, being proactive in reminding them to attend regularly for reviews and signposting to carer support and resources. This could be

helped by seeing the same GP each time the carer visits the surgery, promoting continuity and connection. It also identifies the need for training and raising GPs' awareness to aid early detection and intervention, supporting parental carers in the initial stages of their child's psychosis in getting help.

### **5.7.2 Community-level implications.**

Currently there is a lot of work being done on raising awareness of mental health problems. Nonetheless, there is an overall sense of how mental health problems, particularly psychosis are viewed by society and this must be acknowledged. There is still a high level of stigma attached to these difficulties, which impacts on whether service users and their families share their experiences with other people (Hinshaw & Cicchetti, 2000; Hinshaw, 2000). Moreover, there is a sense that society blames parents for their child's difficulties, leaving them feeling shamed, which stops them talking to other people about their caring role, further isolating them. This contributes to a lack of empathy for how difficult the paternal caring role is and the enduring nature of it. There are also views about fathers not caring or not wanting to be involved in supporting their child (Lamb, 2000). Although, this may be true for a small group of fathers, there is no evidence in this study to support the generalisation of this view. Additionally, there are narratives in society about how men feel and express emotions, in that they usually keep them inside and to themselves and are seen as somewhat feminine if they are more vocal about their feelings (Bird, 1996; Simon & Nath, 2004). This is in contrast to how women are seen and expected to express their emotions. This can leave fathers battling with their own emotional difficulties in relation to their caring roles, possibly impacting on how well they can support their child with psychosis and their wider family.

### **5.7.3 Family-level implications.**

One way that families can be supported is through a family-based therapy, in line with NICE guidelines. These interventions build up and support family bonds reflecting on the strengths within the family, enabling them to cope with their child's psychosis. This would be particularly helpful in the context of the changing relationship that parental carers experience with their child with psychosis, and parents' desire to maintain or form a close relationship with them. It may also help with the meaning-making processes around the psychosis and the impact of the illness on the family. In line with this, members of the family may experience the 'loss' aspect of the illness differently and a family-based therapy could help in facilitating the family to talk about this more openly. Bearing in mind the wish expressed by some participants to protect their children from their 'loss', paternal carers may need their own space to process this (explored further in section 5.9.4).

Additionally, participants spoke of the impact on the relationship with their partners and often found themselves having to support their child with psychosis, as well as their wives (this was another aspect that did not make the final themes due to space limitations). Potentially, couples counselling could be a source of support for both parents and the couples' relationships, which is most likely a source of support for the child they care for.

Joint activities between fathers and their children could also be offered, particularly in the context of men finding it more difficult to talk about their feelings (Bird, 1996; Simon & Nath, 2004) and potentially feeling stigmatised in visiting health premises (Sayers & Spandler, 2015). This is explored further in the following subsection.

#### **5.7.4 Individual-level implications.**

Attending carer support groups has already been identified as a generally helpful forum for carers to share their experiences and feel supported. However, more mothers and other female carers tend to attend. This suggests that more formal support for fathers in their own right may be needed. This may be via individual psychological therapy, which would offer a confidential and safe space for fathers to talk. Although this therapy could be accessed through primary care services, they tend to have certain thresholds, which fathers may or may not meet. Therefore, a pathway could be agreed between services for carers of people with psychosis, in line with Kuipers' (2010) suggestions. This is particularly important given the difficulties accessing family intervention and the subsequent low uptake of this approach. Additionally, psychological therapy could be accessed via the voluntary sector or carer organisations, if they were to develop interventions to support paternal carers.

At the same time, alternative interventions that are not simply verbal therapies or clinic-based could be considered, taking into account the research around how men express emotions and their reluctance to seek support (Sayers & Splander, 2005). It is also reported that men feel stigmatised being seen in clinic settings, are unwilling to talk to female health professionals and confused by the jargon and language used (McKeown et al., 2015). To address this Splander et al. (2013) used a football metaphor and football venues to deliver a non-clinical, group-based therapeutic intervention for men with mental health needs in the UK. They used football as a hook to draw men in and found that the relaxed atmosphere and football analogy enabled attendees to engage in mutually supportive dialogue with each

other. Perhaps the same principle could be applied when offering support to fathers who are carers.

## **5.8 Methodological considerations**

### **5.8.1 Strengths.**

One of the main strengths of this study was that it attempted to explore experiences that have not been researched previously, adding to the paucity of the literature in this area. The study used IPA, which was appropriate for the research question as it allowed a rich and detailed exploration of fathers' experiences of caring for an adult child with psychosis. Therefore, it provides deeper understandings and different perspectives to the existing knowledge and literature of parental experiences of caring for a child with psychosis, as discussed in the introduction.

Reflecting on the recruitment process, initially the first few participants were recruited relatively quickly from attending one carers group. However, the latter part of the recruitment process was much slower and time intensive, requiring numerous emails and visits to various carers groups. Although, this fits with current perceptions and understandings of fathers being difficult to access, find and recruit for research, with commitment to the recruitment process a total of seven participants were recruited. For an IPA study, this was an adequate sample size as Smith et al. (2009) recommends six to eight participants for a small IPA study. Further, the participants had been in their caring roles for an average of 15 years. Not only did this provide a breadth of experiences of being a paternal carer, but also insights into how the role changed as their child's psychosis-related illness progressed and changed over time. Therefore, it was believed from this sample size that rich data was gathered, enabling a comprehensive IPA and development of clear themes which were firmly grounded in the participants' words.

Further, this study addressed IPA's double hermeneutic, (the findings were a co-construction between the participants and myself) through an on-going process of self-reflexivity, supervision, transparency and member checking. Smith et al. (2009) states this is imperative for all IPA studies.

### **5.8.2 Limitations.**

The phenomenological aspect of IPA enables the researcher to explore a person's perception of a particular phenomenon or experience (Smith & Osborn, 2003). This coupled with IPA's idiographic in nature, means that IPA does not offer conclusive answers to a research question and so the findings from this study were just one way that the caring role was experienced by the participants, and this was my interpretation of that way. Caring roles could be experienced and understood in many ways, depending on individuals' experience of their context, and according to different researchers. Therefore, the findings from the current study were limited in their generalisability to all fathers caring for an adult child with psychosis.

Despite the seven participants recruited fitting with the requirements of an IPA study, it was still a small sample size. There was a possibility that the sample in the current study was biased as all fathers were recruited from carer support groups. This suggested that they were invested in their caring role and as demonstrated from the interviews, they had all had contact with mental health services. Experiences of fathers, who were not linked into carer supports forums, have had no contact or limited contact with mental health services may be different. Therefore, the findings may not be representative of all fathers highlighting the limitations in generalising findings from IPA studies.

Additionally, all participants, except one, were still married to the mother of the child they cared for. The experiences of fathers who were no longer in a relationship

with their child's mother (they may be with different partners or single fathers), may be different to those found in the current study. For example, Patrick (who had been a single father) talked about himself much more easily compared to the other fathers (all still in relationship with the mother of the child with psychosis) and was more readily able to reflect on his strengths as a father and individual. An understanding of experiences from these fathers' perspectives would be useful and could be a focus of future research.

Further, all participants cared for a son except for one father, who cared for his daughter. There may be differences in fathers' experiences in caring for a daughter with psychosis versus caring for a son, which would also be helpful to research in future studies. In addition, all participants were the biological father of the child they cared for, except one participant who was a step-father caring for two step-sons with psychosis. Although both these aspects may have provided rich data and insight into this experience, it may have also been overshadowed by the other participants, who were more homogenous on those other aspects.

Regarding the interview process, further follow-up questions could have been asked to clarify participant meaning, as well as questions about gender differences. For example, how the participants' experiences may have differed to their partners' experiences. It should also be noted that the researcher was female and this may have influenced the interviews and analysis process. Addressing this gender disparity in future studies may be helpful.

### **5.8.3 Quality Assurance.**

To support the reader in critiquing the methodology used in this study, I have used the quality criteria standards proposed by Tracy (2010). This enables the reader to assess whether this study's design and methodology was thorough and if

the results were useful. The framework provided by Tracey (2010), includes eight criteria for considering the quality of qualitative research. The current study was evaluated against these criteria in explicitly demonstrating what was done to meet each one. An overview of how the current study meets these eight criteria can be found in Appendix 15.

### **5.9 Suggestions for further research**

The findings from this study suggested a number of possibilities and recommendations for future research, which would add to the current paucity of research and literature in this area.

In terms of diversity, the sample was limited as only one participant identified as coming from an ethnic minority background; the other participants identified as White British. Perhaps this reflected the cultural values and expectations of some ethnic minority groups, regarding the stigma of mental health problems and psychosis, talking about their experiences and engaging with research. It would be helpful to understand the caring experiences of fathers from ethnic minority groups living in the UK, given the higher incidence of psychosis in BME groups (Kirkbride et al., 2012). This would offer additional insights into how culture and ethnicity influence fathers' caring experiences and could be discussed in relation to the findings from the current study. Given that the sample may reflect the contexts of the geographical areas that were recruited from, the study could be carried out in different areas of the UK to see if there was a difference in fathers' lived experiences. It would also be helpful to consider the experiences of fathers who are not in contact with services or carer support groups, which may well overlap with the above.

Additionally, research focussing on gaining a greater understanding of fathers' experiences of caring for a daughter with psychosis would be useful. This links in

with the studies discussed in the systematic review, as many of them highlighted that the majority of participants were caring for a son with psychosis. Moreover, a study looking at parents caring for more than one child with psychosis-related difficulties, would provide greater understanding and insight into the caring role and how parents make sense of their caring experiences.

Within this current study, it emerged that there was a strong sense of unity between participants and their wives (who were the mothers of the child they cared for), which generally enabled and supported fathers in their caring role. So future studies could potentially focus on single fathers, who were no longer with the mother of the child they care for or who have a different partner. The findings also highlighted an extraordinary level of responsibility and unconditional love that fathers appeared to feel towards their children, which remained a key feature in facilitating their caring role. In line with this, the caring experiences of non-biological parents or step-parents (mothers and fathers) could be another aspect investigated by future research. This would be interesting to explore, particularly in relation to the sense of responsibility step-parents may feel for the child they care for, as well as the group of parents noted in Kuipers et al.'s (2010) model and abusive or absent parents.

Further, it emerged from this study that participants continued to feel some confusion and uncertainty related to their child's psychosis, despite being carers for a number of years. Therefore, it may be useful to explore in more detail the issues around this uncertainty, which may contribute to potential interventions to support fathers in these areas.

### **5.10 Personal reflections**

As highlighted in the introduction and in line with the IPA methodology, reflexivity is key in acknowledging my own assumptions, values and meaning-

making processes. Therefore, I have tried to keep a reflexive stance throughout the process and demonstrated this by keeping a reflective diary and having discussions with my peer supervision group and research supervisors. Some of the following were aspects that were shared and explored in these forums.

During the interviews, I was struck by how difficult it was for participants to talk about their own feelings and experiences. I noticed all participants talking about the experiences of their child rather than themselves. Although I anticipated this from my previous experience of working with carers and from the pilot interview, I was surprised by how often I needed to redirect and explicitly ask participants about their experiences. At times, this was uncomfortable for me as I worried about participants feeling pressured and judged. However, this was in contrast to my genuine curiosity regarding how they had made sense of their experiences and the focus of the research.

Additionally, I often felt somewhat limited in being able to ask follow-up questions and delve further into participants' experiences, due to the time constraints. Despite trying to keep an open mind at all times, I heard things that surprised me, that I was not expecting or vastly differed to other participants' experiences. I was also taken aback by the emotional impact of the interviews on participants, as well as on myself. Talking with my peer supervision group and primary research supervisor helped me to consider the potential effects and influences of the experiences I heard from the participants. There was an on-going feeling of uncertainty that I felt during interviews and analysis, which may have been a projection of the uncertainty that the participants were enduring in their lives. At the same time, I wonder if the interview process enabled participants to make some sense of their feelings and experiences.

I think it was important to consider the potential power difference that exist or arise between researcher and participant. I was aware of my position as a mental health professional albeit not yet qualified, and participants possibly seeing me as an expert in the psychosis field or having more knowledge than them, despite not seeing myself in that way. I was concerned that this would impact on what experiences and feelings they chose to share with me, possibly worrying about being judged by a professional. To overcome this, I made a conscious effort to own my researcher position and curious stance throughout my interactions with the participants, rather than focussing on the professional or therapist role. Nonetheless, when the interviews had finished, I found that it was difficult to put this role to one side as I wanted to offer reassurance, empathise with participants and suggest support services if appropriate, which I did. For me, this highlighted the overlap in being a researcher and a clinician, and that it was difficult, if not impossible to keep the two separate. I have learnt that part of my researcher position was influenced by my desire to help others manage emotional difficulties, which will undoubtedly influence future research that I carry out and maybe involved with. However, gaining and maintaining this awareness will help me to manage this in the future, enabling me to be an effective yet compassionate researcher.

I was eager to do justice for the fathers who had shared their experiences with me, in terms of ensuring their voices were heard and trying to do the most comprehensive and thorough IPA analysis. At times, this was pressurising given that I was a novice in this methodology and wanted to keep as much detail as possible, worrying that I would lose something significant. I often felt a huge sense of responsibility of 'doing a god job' for the participants, their families and the children they care for. To a certain extent, I still feel this responsibility as although the thesis

is coming to an end, the research is still on-going with regards to publication and dissemination of the findings to clinical teams.

### **5.12 Conclusion**

This research explored the experiences of fathers caring for an adult child with psychosis, using an IPA approach. Five superordinate themes emerged from the data: 'Father vs. carer'; 'Change in quality of relationship with child'; 'To share or not to share'; 'Acceptance is a struggle' and 'Mental health services: Inconsistency vs. luck'. These results have been discussed referring to the existing body of literature, along with suggestions for future research and implications for clinical practice. The findings highlighted fathers' views of the 'caring role', in that being a carer was not a separate role but part of being a parent. Further, fathers wanted to be and were just as invested and involved as mothers in supporting their child, however, were sometimes restricted by mental health service structures. Therefore, it was important that services reconsider their perceptions of fathers and how they involve and support them in supporting the person they care for.

## 6. REFERENCES

- Addington, J., Coldham, E.L., Jones, B., Ko, T., & Addington, D. (2003). *Acta Psychiatrica Scandinavica*, 108 (4), 285-289.
- Ahern, K.J. (1999). Pearls, Pith and Provocation: Ten tips for reflexive bracketing. *Qualitative Health Research*, 9 (3), 407-411.
- Aldridge, J. (2006). The experiences of children living with and caring for parents with mental illness. *Children and Society*, 22, 253-264.
- Askey, R., Holmshaw, J., Gamble, C., & Gray, R. (2009). What do carers of people with psychosis need from mental health services? Exploring the views of carers, service users and professionals. *Journal of Family Therapy*, 31 (3), 310-331.
- Barker, C., Pistrang, N., & Elliot, R. (2002). *Research Methods in Clinical Psychology: An Introduction for Students and Practitioners*. (2<sup>nd</sup> Ed.). Chichester: John Wiley & Sons, Ltd.
- Bebbington, P. E., Bhugra, D., Brugha T., Singleton, N., Farrell, M., Jenkins, R., et al. (2004). Psychosis, victimisation and childhood disadvantage. Evidence from the second British National Survey of Psychiatric Morbidity. *The British Journal of Psychiatry*, 185, 220-6.
- Bech, P. (1993). *Rating scales for psychopathology, health status and quality of life*. New York: Springer-Verlag.
- Biggerstaff, D. & Thompson, A.R. (2008). Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology*, 5, 173-183.
- Bird, S. R. (1996). Welcome to the men's club: Homosociality and the maintenance of hegemonic masculinity. *Gender & society*, 10(2), 120-132

- Bowlby J. (1982). *Attachment and Loss, Vol. I. Attachment*. (2nd Ed.). New York: Basic Books.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3* (2), 77–101.
- British Psychological Society's Division of Clinical Psychology. (2014). *Understanding Psychosis and Schizophrenia*. London: BPS.
- Cabrera, N., Tamis-LeMonda, C. S., Bradley, R. H., Hofferth, S., & Lamb, M. E. (2000). Fatherhood in the twenty-first century. *Child Development, 71* (1), 127-136.
- Carer's Trust (n.d.) *What is a carer?* Retrieved 9 November 2016 from <http://www.carers.org/whats-a-carer>
- Carers UK. (2015a). *Facts about Carers: Policy Briefing 2015*. Retrieved from [carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2015](http://carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2015)
- Carers UK. (2015b). *State of Caring 2015*. London: Carers UK. Retrieved from [carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015](http://carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015)
- [Charmaz, K. \(2015\). Grounded Theory. In Smith, J. A. \(Ed.\). Qualitative psychology: a practical guide to research methods. Sage.](#)
- Chan, B. W. (2008). Violence against caregivers by relatives with schizophrenia. *International Journal of Forensic Mental Health, 7* (1), 65–81.
- Chen, F., & Greenberg, J.S. (2004). A positive aspect of caregiving: The influence of social support on caregiving gains for family members of relatives with schizophrenia. *Community Mental Health Journal, 40* (5), 423-435.
- Critical Appraisal Skills Programme (2017). *CASP Qualitative Checklist*. [online] Retrieved from: <http://www.casp-uk.net/checklists>

- Darmi, E., Bellali, T., Papazoglou, I., Karamitri I., & Papadatou, D. (2017). Caring for an intimate stranger: parenting a child with psychosis. *Journal of Psychiatric and Mental Health Nursing*, 24 (4),194-202. doi: 10.1111/jpm
- Department of Health. (1999). *Patient and Public Involvement in the new NHS*. London: Department of Health.
- Department of Health. (2005). *Research Governance Framework for Health and Social Care* (2nd Edn). London: Department of Health.
- Doucet, A. (2004). "It's almost like I have no job, but I don't get paid": Fathers at home reconfiguring work, care, and masculinity. *Fathering*, 2, 277-303.
- Edwards, D., & Potter, J. (1992). *Discursive Psychology*. London: Sage Publications.
- Emerson, P., & Frost, S. (2009). *Critical Narrative Analysis in Psychology: A Guide to Practice*. Basingstoke: Palgrave Macmillan.
- Elliott, R., Fischer, C.T., & Rennie, D.L. (1999). Evolving guidelines for the publication of qualitative research studies in psychology and evolving fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Ewertzon, M., Lütznén, K., Svensson, E., & Andershed, B. (2010). Family members' involvement in psychiatric care: experiences of the healthcare professionals' approach and feeling of alienation. *Journal of Psychiatric and Mental Health Nursing*, 17 (5), 422-432.
- Faulkner, A. (2012). Participation and Service User Involvement. In D. Harper, & R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 39-54). Chichester: John Wiley & Sons, Ltd.

- Ferriter, M., & Huband, N. (2003). Experiences of parents with a son or daughter suffering from schizophrenia. *Journal of Psychiatric and Mental Health Nursing, 10* (5), 552-560.
- Field, A. (2009). *Discovering statistics using SPSS*. Sage publications.
- Finlay, L. (2011). *Phenomenology for Therapists: Researching the Lived World*. John Wiley & Sons.
- Fraser, C., & Warr, D. J. (2009). Challenging roles: Insights into issues for men caring for family members with mental illness. *American journal of men's health, 3* (1), 36-49.
- Gergen, K. J. (2009). *Realities and relationships: Soundings in social construction*. Harvard university press.
- Glaser, B.G., & Strauss, A.L. (1967). *The Discovery of Grounded Theory*. Chicago: Aldine.
- Guberman, N., Maheu, P., & Maillé, C. (1992). Women as family caregivers: Why do they care?. *The Gerontologist, 32* (5), 607-617.
- Gutiérrez-Maldonado, J., Caqueo-Úrizar, A., & Kavanagh, D. J. (2005). Burden of care and general health in families of patients with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology, 40* (11), 899-904.
- Hayes, L., Hawthorne, G., Farhall, J., O'Hanlon, B., & Harvey, C. (2015). Quality of life and social isolation among caregivers of adults with schizophrenia: Policy and outcomes. *Community mental health journal, 51* (5), 591-597.
- Hefferon, K., & Gil-Rodriguez, E. (2011). Interpretative phenomenological analysis. *The Psychologist, 24* (10), 756-759.
- Hickman, G., Newton, E., Fenton, K., Thompson, J., Boden, Z.V., & Larkin, M. (2016). The experiential impact of hospitalisation: Parents' accounts of caring

- for young people with early psychosis. *Clinical Child Psychology and Psychiatry*, 21 (1):145-55. doi: 10.1177/1359104515581716.
- Hinshaw, S. P. (2005). The stigmatisation of mental illness in children and parents: Developmental issues, family concerns, and research needs. *Journal of Child Psychology and Psychiatry*, 46 (7), 714-734.
- Hinshaw, S. P., & Cicchetti, D. (2000). Stigma and mental disorder: Conceptions of illness, public attitudes, personal disclosure and social policy. *Development and Psychopathology*, 12, 555-598.
- H.M. Government. (1999). *Caring about Carers: A National Strategy for Carers*. London: HMSO.
- HQIP and the Royal College of Psychiatrists. (2016). Report of the Early Intervention in Psychosis audit. Retrieved 17 October 2016 from <http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/earlyinterventionpsychosis.aspx>
- Joyce, J., Leese, M., Kuipers, E., Szmukler, G., Harris, T., & Staples, E. (2003). Evaluating a model of caregiving for people with psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 38 (4), 189-195.
- Jungbauer, J., & Angermeyer, & M. C. (2004). Living with a Schizophrenic Patient: A Comparative Study of Burden as It Affects Parents and Spouses. *Psychiatry*, 65 (2), 110-123.
- Jungbauer, J., Stelling, K., Dietrich, S., & Angermeyer, & M. C. (2004). Schizophrenia: problems of separation in families. *Journal of advanced nursing*, 47 (6), 605-613.

- Kimmel, M.S. (1994). Masculinity as homophobia: Fear, shame and silence in the construction of gender identity. In H. Brod & M. Kaufman (Eds.), *Theorizing masculinities* (pp. 119-141). Thousand Oaks, CA: Sage Publications.
- Kingston, C., Onwumere, J., Keen, N., Ruffell, T., & Kuipers, E. (2015). Posttraumatic stress symptoms (PTSS) in caregivers of people with psychosis and associations with caregiving experiences. *Journal of Trauma and Dissociation*, 17 (3), 307-321, [doi.org/10.1080/15299732.2015.1089969](https://doi.org/10.1080/15299732.2015.1089969)
- Kirkbride, J. B., Errazuriz, A., Croudace, T. J., Morgan, C., Jackson, D., Boydell, J., & Jones, P. B. (2012). Incidence of schizophrenia and other psychoses in England, 1950–2009: a systematic review and meta-analyses. *PLOS One*, 7 (3), [doi.org/10.1371/journal.pone.0031660](https://doi.org/10.1371/journal.pone.0031660)
- Krippendorff, K. (2004). *Content analysis: An Introduction to its Methodology* (2nd ed.). London: Sage Publications.
- Kuipers, E. (2010). Time for a separate psychosis caregiver service? *Journal of Mental Health*, 19 (5), 401-404.
- Kuipers, E., & Bebbington, P. E. (2010). Relatives as a resource in the management of functional illness. *The British Journal of Psychiatry*, 147, 465-70.
- Kuipers, E., Onwumere, J., & Bebbington, P. (2010). Cognitive model of caregiving in psychosis. *The British Journal of Psychiatry*, 196, 259-265.
- Lamb, M. E. (2000). The history of research on father involvement: An overview. *Marriage & Family Review*, 29 (2-3), 23-42
- Larkin, M., & Thompson, A.R. (2012). Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In D. Harper, & R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: A*

- Guide for Students and Practitioners* (pp. 39-54). Chichester: John Wiley & Sons, Ltd.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*, 102-120.
- Lavis, A., Lester, H., Everard, L., Freemantle, N., Amos, T., Fowler, D., Hodgekins, J., Jones, P., Marshall, M., Sharma, V., Larsen, J., McCrone, P., Singh, S., Smith, J., & Birchwood, M. (2015). Layers of listening: Qualitative analysis of the impact of early intervention services for first-episode psychosis on carers' experiences. *British Journal of Psychiatry, 207* (2), 135-142.
- Magliano, L., Fadden, G., Madianos, M., de Almeida, J. M., Held, T., Guarneri, M., Marasco, C., Tosini, P., & Maj, M. (1998). Burden on the families of patients with schizophrenia: results of the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology, 33* (9), 405-12.
- Magliano, L., Fiorillo, A., Malangone, C., Marasco, C., Guarneri, M., Maj, M., et al. (2003). The effect of social network on burden and pessimism in relatives of patients with schizophrenia. *American Journal of Orthopsychiatry, 73*, 302-9.
- Magliano, L., Fiorillo, A., De Rosa, C., Malangone, C., Maj, M., & National Mental Health Project Working Group. (2005). Family burden in long-term diseases: a comparative study in schizophrenia vs. physical disorders. *Social science & medicine, 61*(2), 313-322.
- McAuliffe, R., O'Connor, L., & Meagher, D. (2014). Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study. *Journal of Psychiatric Mental Health Nursing, 21* (2), 145-53. doi:10.1111/jpm.12065.

- McCann, T.V., Lubman, D.I., & Clark, E. (2011a). First-time primary caregivers' experience of caring for young adults with first-episode psychosis. *Schizophrenia Bulletin*, 37 (2), 381-8. doi:10.1093/schbul/sbp085.
- McCann, T.V., Lubman, D.I., & Clark, E. (2011b). First-time primary caregivers' experience accessing first-episode psychosis. *Early Intervention in Psychiatry*, 5 (2), 156-162.
- McCann, T. V., Bamberg, J. & McCann, F. (2015). Family carers' experience of caring for an older parent with severe and persistent mental illness. *International Journal of Mental Health Nursing*, 24, 203-212.
- McKeown, M., Roy, A., & Spandler, H. (2015). 'You'll never walk alone': Supportive social relations in a football and mental health project. *International Journal of Mental Health Nursing*, 24, 360-369.
- McNair, R., Taft, A., & Hegarty, K. (2008). Using reflexivity to enhance in-depth interviewing skills for the clinician researcher. *BMC Medical Research Methodology*, 8 (1), 73.
- Muench, J., & Hamer, A. M. (2010). Adverse effects of antipsychotic medications. *American Family Physician Journal*, 81 (5), 617-622.
- National Institute of Health and Care Excellence. (2014). *Psychosis and Schizophrenia in adults: treatment and management (178)*. London: National Institute for Health and Care Excellence.
- Office for National Statistics (2013). *Statistical Bulletin*. London: TSO.
- Onwumere, J., Kuipers, E., Bebbington, P., Dunn, G., Fowler, D., Freeman, D., & Garety, P. (2008). Caregiving and illness beliefs in the course of psychotic illness. *The Canadian Journal of Psychiatry*, 53 (7), 460-468.

- Onwumere, J., Shiers, D., & Chew-Graham, C. (2016). Understanding the needs of carers of people with psychosis in primary care. *The British Journal of General Practice: The Journal of the Royal College of General Practitioners*, 66 (649), 400-401. doi:10.3399/bjgp16X686209
- Onwumere, J., Parkyn, G., Learmonth, S., & Kuipers, E. (2018). The last taboo: The experience of violence in first-episode psychosis caregiving relationships. *Psychology and Psychotherapy: Theory, Research and Practice*. doi: epdf/10.1111/papt.12173
- Patterson, P., Birchwood, M., & Cochrane, R. (2005). Expressed emotion as an adaptation to loss: Prospective study in first-episode psychosis. *The British Journal of Psychiatry*, 187, 59-64.
- Perlick, D. A., Hohenstein, J. M., Clarkin, J. F., Kaczynski, R., & Rosenheck, R. A. (2005). Use of mental health and primary care services by caregivers of patients with bipolar disorder: a preliminary study. *Bipolar Disorders*, 7 (2), 126-135.
- Pleck, E. H., & Pleck, J. H. (1997). Fatherhood ideals in the United States: Historical dimensions. In M. E. Lamb (Ed.), *The role of the father in child development* (3<sup>rd</sup> ed.). New York: Wiley.
- Porter, S. E., & Robinson, J. C. (2011). *Hermeneutics: An introduction to interpretive theory*. Chicago: Wm. B. Eerdmans Publishing.
- Raune, D., Kuipers, E., & Bebbington, P. E. (2004). Expressed emotion at first-episode psychosis: investigating a carer appraisal model. *The British Journal of Psychiatry*, 184 (4), 321-6.

- Raymond, K.Y., Willis, D.G., & Sullivan-Bolyai, S. (2017). Parents Caring For Adult Children With Serious Mental Illness. *Journal of the American Psychiatric Nurses Association*, 23 (2), 119-132. doi: 10.1177/1078390316685404.
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. London: Sage.
- Rochlen, A. B., McKelley, R. A., & Whittaker, T. A. (2010). Stay-at-home fathers' reasons for entering the role and stigma experiences: A preliminary report. *Psychology of Men & Masculinity*, 11 (4), 279-285.
- Roick, C., Heider, D., Bebbington, P.E., Angermeyer, M.C., Azorin, J.M., Brugha, T.S., et al. (2007). Burden on caregivers with schizophrenia: comparison between Germany and Britain. *British Journal of Psychiatry*, 190, 333-38.
- Sayers P., & Spandler H. (2016). It's a Goal: A Football-Based Mental Health Programme. In D. Conrad., & White A. (eds) *Sports-Based Health Interventions*. Springer: New York.
- Schizophrenia Commission. (2012). The Abandoned Illness: A Report from the Schizophrenia Commission. Rethink Mental Illness. Retrieved 9 November 2016 from <https://www.sussex.ac.uk/webteam/gateway/file.php?name=tsc-executive-summary1.pdf&site=75>
- Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family-caregivers of people with mental illnesses. *World Journal of Psychiatry*, 6 (1), 7.
- Shotter, J. (1993) *Conversational Realities. Constructing Life through Language*. London: Sage.
- Simon, R. W., & Nath, L. E. (2004). Gender and emotion in the United States: Do men and women differ in self-reports of feelings and expressive behavior?. *American journal of sociology*, 109 (5), 1137-1176

- Sin, J., Moone, N., & Wellman, N. (2005). Developing services for the carers of young adults with early-onset psychosis – Listening to their experiences and needs. *Journal of Psychiatric and Mental Health Nursing*, 12 (5), 589-597.
- Smith, J. A., & Osborn, M. (2003). Interpretative Phenomenological Analysis. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods* (2nd ed.). London: Sage.
- Smith, J.A., & Osburn, M. (2008). Interpretive Phenomenological Analysis. In J. A. Smith (Ed.). *Qualitative Psychology: A Practical Guide to Research Methods* (2<sup>nd</sup> Ed., pp.51-80.). London: Sage.
- Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretive Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health psychology review*, 5 (1), 9-27.
- Spandler, S., McKeown, M., Roy, A., & Hurley, M. (2015). Football metaphor and mental well-being: An evaluation of the *It's a Goal!* Programme. *Journal of Mental Health*, 22 (6), 544-554.
- Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). *Quality in Qualitative Evaluation: A framework for assessing research evidence*. London: Government Chief Social Researcher's Office.
- Szmukler, G., Burgess, P., Herman, H., Benson, A., Colusa, S., & Bloch, S. (1996). Caring for relatives with serious mental illness: the development of the experience of caregiving inventory. *Social psychiatry and psychiatric epidemiology*, 31 (3-4), 137-148.

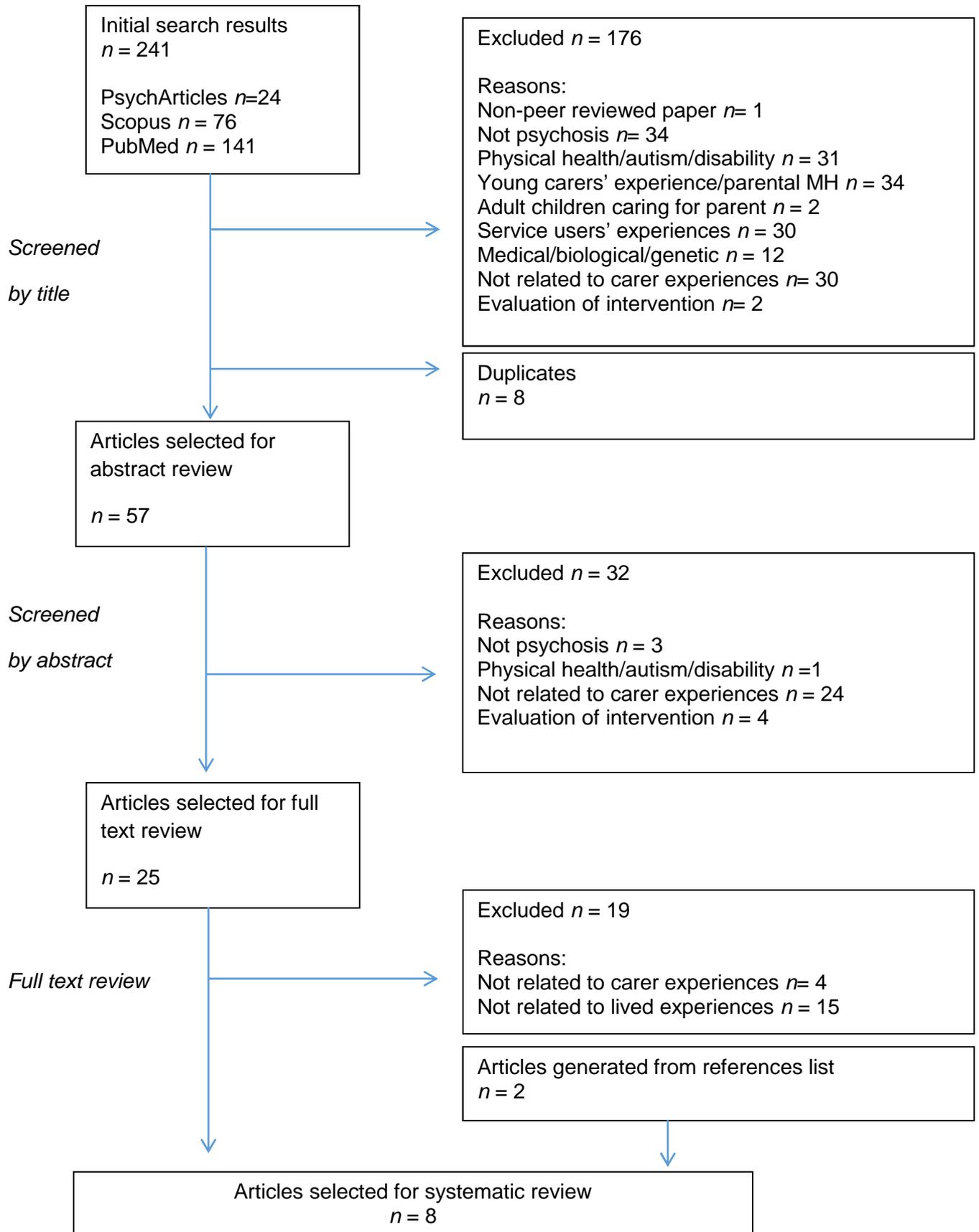
- The Care Act. (2016). Factsheet 8: The Law for Carers. Retrieved 14 November 2016 from <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-8-the-law-for-carers>
- Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, 16 (10), 837-851.
- Wagstaff, C., Jeong, H., Nolan, M., Wilson, T., Tweedlie, J., Phillips, E., Senu, H., & Holland, F. (2014). The Accordion and the Deep Bowl of Spaghetti: Eight Researchers' Experiences of Using IPA as a Methodology. *The Qualitative Report*, 19 (24), 1-15.
- Wainwright, L.D., Glentworth, D., Haddock, G., Bentley, R., & Lobban, F. (2015). What do relatives experience when supporting someone with early psychosis? *Psychology and Psychotherapy: Theory, Research and Practice*, 88, 105-119.
- Wall, G., & Arnold, S. (2007). How Involved is Involved Fathering? An Exploration of the Contemporary Culture of Fatherhood. *Gender and Society*, 21 (4), 508-527.
- White, C. (2013). 2011 Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001. ONS. Retrieved from [ons.gov.uk/ons/dcp171766\\_300039](https://ons.gov.uk/ons/dcp171766_300039).
- Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-Hill Education (UK).
- World Health Organization. Schizophrenia fact sheet. Retrieved 9 May 2018 from <http://www.who.int/mediacentre/factsheets/fs397/en/>
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15 (2), 215-228.

Yardley, L. (2008). Demonstrating Validity in Qualitative Psychology. In J.A. Smith (Ed.). *Qualitative Psychology: A Practical Guide to Research Methods* (2nd Ed., pp. 235-251). London: Sage.

Yesufu-Udechuku, A., Bronwyn, H., Mayo-Wilson, E., Young, N., Woodhams, P., Shiers, D., Kuipers, E., & Kendall, T. (2015). Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis. *The British Journal of Psychiatry*, 206, 268-274.

## 7. APPENDICES

### Appendix 1: Flow Chart of Literature Search Process



## Appendix 2: Summary & Evaluation of Studies in Literature Review

Authors, year & Title	Type & Aim	Participants	Methodology	Results and Conclusions	Strengths & Limitations
<p>McAuliffe, O'Connor &amp; Meagher (2014)</p> <p>Parents' experience of living with and caring for an adult son or daughter with schizophrenia at home in Ireland: a qualitative study</p>	<p>Qualitative</p> <p>To explore the experience of parents living with, and caring for an adult child with schizophrenia</p>	<p>6 parents (5 mothers, 1 father)</p>	<p>Semi-structured interviews.</p> <p>Thematic analysis.</p>	<p>Four themes:</p> <ul style="list-style-type: none"> <li>-psychological tsunami</li> <li>-intricacies of caring</li> <li>-coping with enduring illness</li> <li>-uncertain pathway</li> </ul> <p>Parents report severe psychological distress when child diagnosed with schizophrenia. Initial deep loss followed by acceptance. Love and responsibility helped to give meaning to their role.</p>	<p>Focus on lived experience - Adding to limited body of research into parental caring experiences.</p> <p>Range of lengths of caring roles from 6 to 25 years.</p> <p>Based on Irish population</p> <p>Small sample size. Mainly mothers, only one father – feeds into idea that men do not want to talk or are not involved in caring responsibilities.</p> <p>Selection bias – those who identify as carers and are already linked in with mental services.</p>
<p>Darmi, Bellali, Papazoglou, Karamitri, &amp; Papadatou (2017)</p> <p>Caring for an intimate stranger: parenting a child with psychosis</p>	<p>Qualitative</p> <p>Explore the parents' lived experience of caring for a child with psychosis</p>	<p>16 parents (14 mothers, 2 fathers)</p>	<p>Semi-structured interview format utilised.</p> <p>Interviews transcribed and analysed using IPA.</p>	<p>Themes identified:</p> <ul style="list-style-type: none"> <li>-the psychosis experience</li> <li>-redefinition of the parent-child relationship</li> <li>-challenges of parenting a child with psychosis</li> </ul>	<p>Greek population</p> <p>Adding to limited body of research on how parental carers make sense of their caring experiences.</p> <p>Good sample size but mostly mothers, fathers unwilling to participate</p> <p>Limited number of parents with daughters.</p>
<p>Raymond, Willis, &amp; Sullivan-Bolyai</p>	<p>Qualitative</p>	<p>30 parents (22 mothers, 8</p>	<p>Semi-structured interview format</p>	<p>Four themes:</p>	<p>Adding to limited body of research on how parental carers make sense of their caring</p>

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

<p>(2017)</p> <p>Parents Caring For Adult Children With Serious Mental Illness</p>	<p>To examine parents' management styles when caring for adult children with SMI and their perspectives what community approaches would support family functioning.</p>	<p>fathers)</p>	<p>utilised.</p> <p>Interviews transcribed and analysed using content analysis</p>	<p>-prolonged, difficult and confusing phases that family undergo in caring for a child with SMI.</p> <p>Phases are progressive, moving from recognising illness to redefining family life.</p>	<p>experiences.</p> <p>Based on US population</p> <p>More mothers than fathers so study does not reflect potential differences in caregiving by gender.</p> <p>Content analysis is a purely descriptive method. It describes what is there, but may not reveal the underlying motives for the observed pattern ('what' but not 'why'). The analysis is limited by availability of material so observations may not be an accurate reflection of reality.</p> <p>SMI includes schizophrenia-spectrum disorders as well as bipolar. Majority had diagnosis of schizoaffective (n=21) and then bipolar (n=9) and schizophrenia (n=4). Caring experiences of bipolar could potentially be very different to psychosis as treatment guidelines, services and understanding of these diagnosis is different.</p> <p>Biased sample as most already in contact with services and so have more knowledge of SMI and services than other parents.</p>
<p>McCann, Lubman, &amp; Clark (2011a)</p>	<p>Qualitative</p> <p>To understand</p>	<p>20 caregivers (17 female, 3 male; 17</p>	<p>Semi-structured interviews, transcribed and</p>	<p>Six themes:</p>	<p>Focus on lived experience and meaning-making. Adding to limited body of research</p>

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

<p>First-time primary caregivers' experience of caring for young adults with first-episode psychosis</p>	<p>the experience of first-time primary caregivers of young adults with FEP.</p>	<p>parents, 1 spouse, 1 grandparent, 1 aunt/uncle)</p>	<p>analysed using IPA</p>	<ul style="list-style-type: none"> <li>-burdensome responsibility</li> <li>-roller coaster and unpredictable experience</li> <li>-feeling responsible for their illness</li> <li>-coming to terms with the change</li> <li>-becoming closer</li> <li>-maintaining hope</li> </ul> <p>Caring is a roller coaster but eventually carer comes to terms with changes in relationship.</p> <p>Caregivers feel responsible for young person's illness</p> <p>Relationship between carer and recipient becomes closer</p>	<p>into parental caring experiences.</p> <p>Good sample size – although mainly female carers and no information on how many mothers/fathers. Mainly females, who may have different experiences to males.</p> <p>Based on Australian population.</p> <p>Difficult to generalise – bound to the context.</p> <p>Biased population – carers who already identify themselves as carers and engaged in services.</p> <p>Specific to FEP, does not capture broader experiences or how caring experience may change as illness progresses</p>
<p>Addington, Coldham, Jones, Ko, &amp; Addington (2003)</p> <p>The first episode of psychosis: The experience of relatives</p>	<p>Quantitative.</p> <p>This study aimed to determine the extent of and the correlates of the distress</p>	<p>236 family members (173 mothers, 28 fathers, 25 spouse, 12 other relative)</p>	<p>Psychological General Well-Being Scale</p> <p>Experience of Caregiving</p>	<p>No differences in symptoms for patients with and without family involved.</p> <p>No differences between those living with their relative and those who did not – equally distressed and concerned.</p>	<p>ECI gold standard measure for caregiving in psychosis.</p> <p>Inferential statistics used to determine impact of patient characteristics on caregiving experiences.</p> <p>No information on hours of contact.</p>

FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

	<p>and impact of care families of patients with FEP were experiencing when they first came in for treatment.</p>		<p>Inventory</p>	<p>All families moderately distressed; both measure outcomes were highly correlated.</p> <p>Mothers had higher scores of ECI than spouses.</p> <p>Family's appraisal of the impact of the illness was associated with their psychological well-being.</p>	<p>Fair sample size.</p> <p>Representing community sample, rather than admitted to hospital sample.</p> <p>Based on Canadian population.</p> <p>Studied carried out with carers at start of FEP – experiences may changes are later stages of their relatives' psychosis – no longitudinal information.</p> <p>No direct caring experiences reported. Fathers under-represented as 12% fathers and 73% mothers.</p> <p>No focus on lived experience</p>
--	--	--	------------------	---	---

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

<p>Sin, Moone, &amp; Wellman (2005)</p> <p>Developing services for the carers of young adults with early-onset psychosis - Listening to their experiences and needs</p>	<p>Qualitative</p> <p>To explore carers' experience of caring for a young adult with FEP and their needs for an EIP service.</p>	<p>11 parents (7 mothers, 4 fathers)</p>	<p>Semi-structured interviews, transcribed and analysed using IPA</p>	<p>All carers were providing a range of practical, emotional and financial support for their child.</p> <p>They liaised and engaged with mental health services.</p> <p>Carers felt invisible and undervalued by services. They felt they had unmet needs with regards to information and support. They felt their child's psychosis had had a traumatic impact on their lives.</p>	<p>Focus on lived experience and meaning-making. Adding to limited body of research into parental caring experiences.</p> <p>Good sample size – although mainly female carers and no information on how many mothers/fathers. Mainly females, who may have different experiences to males.</p> <p>UK based study</p> <p>Biased population – carers who already identify themselves as carers and engaged in services.</p> <p>Specific to accessing FEP services, less insight into broader caring experiences and as illness progresses.</p>
<p>Mccann, Lubman, &amp; Clark (2011b)</p> <p>First-time primary caregivers' experience accessing first-episode psychosis services</p>	<p>Qualitative</p> <p>To describe lived experience of FEP primary caregivers on accessing FEP services.</p>	<p>20 caregivers (17 female, 3 male; 17 parents; 1 spouse, 1 grandparent, 1 aunt/uncle)</p>	<p>Semi-structured interviews, transcribed and analysed using IPA</p>	<p>Three themes:</p> <ul style="list-style-type: none"> <li>-general practitioners can be a barriers as a means of access to FEP services</li> <li>-service-focussed and carer-focussed barriers when accessing FEP services</li> <li>-knowledge, service experience and assertiveness enhance access</li> </ul>	<p>Focus on lived experience and meaning-making. Adding to limited body of research into parental caring experiences.</p> <p>Good sample size – although mainly female carers and no information on how many mothers/fathers. Mainly females, who may have different experiences to males.</p> <p>Based on Australian population.</p> <p>Difficult to generalise.</p> <p>Biased population – carers who already</p>

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

					<p>identify themselves as carers and engaged in services.</p> <p>Specific to accessing FEP services, less insight into broader caring experiences and as illness progresses</p>
<p>Hickman, Newton, Fenton, Thompson, Boden, &amp; Larkin (2016)</p> <p>The experiential impact of hospitalisation: Parents' accounts of caring for young people with early psychosis</p>	<p>Qualitative</p> <p>To examine the experiential impact of hospitalisation on the parents of young people with early psychosis</p>	<p>6 parents (4 mothers, 2 fathers)</p>	<p>Semi-structured interview format utilised.</p> <p>Interviews transcribed and analysed using IPA.</p>	<p>Five themes:</p> <ul style="list-style-type: none"> <li>-Accepting and blaming</li> <li>Feeling out of control</li> <li>-Hospitalisation as temporary containment</li> <li>-Feeling let down by services</li> <li>-Stigma</li> </ul> <p>Aspects of hospitalisation seen as negative but also seen as relief, safety and containment for parents.</p>	<p>Implications resonates with current government mental health strategy with regard to how services can engage and include carers in the mental health system</p> <p>Focus on lived experience and meaning-making</p> <p>UK based study – NHS context</p> <p>Fair sample – more mothers and fathers</p> <p>Specific to hospitalisation, less insight into broader caring experiences</p>

### Appendix 3: Quality of the Research utilised in Literature Review

Qualitative Appraisal using CASP checklist (CASP, 2017)

	Clear statement of aims?	Qualitative method appropriate?	Design appropriate to address aims, justified design/method?	Recruitment strategy appropriate?	Data collected appropriately?	Evidence of self-reflexivity of researcher?	Ethical issues considered?	Data analysis sufficiently rigorous?	Clear statement of findings, credibility addressed?	How valuable is the research?
McAuliffe et al. (2014)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell (Too little info to judge)	Yes	Valuable contribution, clear clinical implications
Darmi et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes		Valuable contribution, clear clinical implications
Raymond et al. (2017)	Yes	Yes	Can't tell (No justification for design)	Yes	Yes	No	Yes	Can't tell (Too little info to judge)		Limited due to lack of info on credibility

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

McCann et al. (2011a)	Yes	Yes	Yes	Yes	Yes	No	No (No explicit info provided)	Yes		Limited due to lack of info on credibility
Sin et al. (2005)	Yes	Yes	Yes	Yes	Yes	No	No (No explicit info provided)	Yes		Valuable contribution, clear clinical implications
Mccann et al. (2011b)	Yes	Yes	Yes	Yes	Yes	No	No (No explicit info provided)	Yes		Limited due to lack of info on credibility
Hickman et al.(2016)	Yes	Yes	Yes	Yes	Yes	Yes	No (No explicit info provided)	Yes		Valuable contribution, clear clinical implications

Quantitative Appraisal using Elliot, Fischer and Rennie (1999)

	Explicit scientific context and purpose	Appropriate methods	Respect for participants	Specification of methods	Appropriate discussion	Clarity of presentation	Contribution to knowledge
Addington et al. (2003)	The researchers clearly state the aims of the research and outline the context and previous research.	The methods used were appropriate for the aims and research questions of this research.	There was no mention of ethical considerations in regard to  Informed consent, confidentiality or potential harm to participants.	There were limited details on the type of statistical analyses carried out on the data.  Details of the measures used are specified.	The discussion offers a brief explanation of the results, limitations and clinical implications to the reader.	The paper is presented in a way that is easy to read. The researchers use headings and tables (in the results section) to enable this.	The paper provides some insight into the experiences of relatives caring for a person with psychosis as measured by the two questionnaires used.  However, as it is a quantitative study, no understanding into the lived experiences of carers is offered.

## Appendix 4: Ethics approval from



HEALTH SCIENCES ENGINEERING & TECHNOLOGY ECDA

### ETHICS APPROVAL NOTIFICATION

TO: Bina Sharma  
CC: Saskia Keville  
FROM: Dr Amanda Ludlow, Health, Sciences, Engineering & Technology ECDA Vice Chair  
DATE: 27/04/2017

---

Protocol number: LMS/PGR/UH/02801

Title of study: Fathers' experiences of caring for a child with psychosis: A qualitative study.

Your application for ethics approval has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

This approval is valid:

From: 27/04/2017

To: 01/09/2018

Additional workers: no additional workers named.  
Please note:

**If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete.**

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

**Appendix 5: Amended Ethics approval form****HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA****ETHICS APPROVAL NOTIFICATION**

**TO** Bina Sharma  
**CC** Dr Saskia Keville  
**FROM** Dr Simon Trainis, Health, Sciences, Engineering & Technology ECDA Chair  
**DATE** 16/05/2017

---

Protocol number: aLMS/PGR/UH/02801(2)

Title of study: Fathers' experiences of caring for a child with psychosis: A qualitative study. .

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Modification: Extend the recruitment process to include a snowballing effect, as well as use of websites and Facebook pages.

This approval is valid:

From: 27/04/2017

To: 01/09/2017

**Additional workers: no additional workers named.**

**Please note:**

## Appendix 6: Recruitment Summary Email

Dear Sir/Madam,

My name is Bina Sharma and I am a Clinical Psychology Trainee at the University of Hertfordshire. I am emailing with regards to my research study looking at fathers' experiences of caring for a child with psychosis. For my thesis project, I am interviewing fathers who care for a child (18+) with psychosis. The aim of the study is to explore how fathers have made sense of and understood their experiences as a carer. I have received full ethical approval for this study by The University of Hertfordshire Health and Human Sciences Ethics Committee.

I was wondering if it would be possible to forward information about the study to the carers who attend the support group/s. I have included a summary of the study and some about information that can be emailed out along with the attached information sheet and consent form. Alternatively, I'd be happy to come and talk about my research at a local carers group, if it was felt that would be appropriate.

Your support would be greatly appreciated. Thank you for your time.

### *Summary*

My study is looking at fathers' experiences of caring for an adult child with psychosis. The statistics show that at any one time around 120, 000 people will be caring for a person with psychosis. Previous research has looked at parental experiences of caring, which has highlighted the rewarding nature of caring but also the difficulties associated with this role. However, the majority of these parents in these studies have been mothers, so little is known about fathers' experiences. Therefore, I would like to interview fathers to ask them about their caring experiences and how they have made sense of them. For the study, I am looking to interview eight participants. The interviews will last approximately an hour and can take place at the University of Hertfordshire or your home, whichever is easiest for you to access.

### *About me*

I am currently in the final year of the Clinical Psychology Doctorate at the University of Hertfordshire. I have a longstanding interest in working with people with psychosis, carers and families. Prior to training, I worked in a specialist psychosis service at the Maudsley Hospital, which was heavily focussed on including families and carers in therapy as well as increasing the awareness of the needs of carers for people with psychosis.

I have received full ethical approval for this study by The University of Hertfordshire Health and Human Sciences Ethics Committee.

To participate and learn more about this project, please email me at [b.s.sharma@herts.ac.uk](mailto:b.s.sharma@herts.ac.uk).

Your interest and participation is greatly appreciated.

Best Wishes,

**Bina Sharma**

Trainee Clinical Psychologist

Health & Human Sciences Research Institute | Health Research Building | College Lane  
Campus | University of Hertfordshire | Hatfield | AL10 9AB | E: [b.s.sharma@herts.ac.uk](mailto:b.s.sharma@herts.ac.uk)

## Appendix 7: Participant Information Sheet and Consent Form

### UNIVERSITY OF HERTFORDSHIRE

#### ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS (‘ETHICS COMMITTEE’)

#### FORM EC6: PARTICIPANT INFORMATION SHEET

##### Title of study

Fathers' experiences of caring for a child (18+) with psychosis: a qualitative study.

##### Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part.

The University's regulations governing the conduct of studies involving human participants can be accessed via this link: <http://sitem.herts.ac.uk/secreg/upr/RE01.htm>

Thank you for reading this.

##### What is the purpose of this study?

This investigation aims to explore how fathers of adult children with psychosis have understood and made sense of their care-giving experiences by carrying out semi-structured interviews.

##### Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect any treatment/care that you or the person you care for may receive (should this be relevant).

##### Are there any age or other restrictions that may prevent me from participating?

You must be:

- A father/father figure of a child (18+) with psychosis
- Fluent in English

##### How long will my part in the study take?

If you decide to take part in this study, you will be involved in an interview for lasting approximately one hour depending how much information you are able to give.

##### What will happen to me if I take part?

The first thing to happen will be a discussion on where the interview will take place depending on what you are most comfortable with, the options are at your own home, at the University of Hertfordshire or a Skype interview. Once this is confirmed, a date will be set and you will be sent a demographic questionnaire to fill out, along with the interview schedule for you to understand the types of questions that will be asked. Then the interview will be conducted and recorded during the set date.

**What are the possible disadvantages, risks or side effects of taking part?**

The interview could potentially bring up difficult emotions and distressing memories.

**What are the possible benefits of taking part?**

It allows us to hear the perspective and experiences of fathers caring for a child (18+) with psychosis. Therefore, hopefully this will enhance current knowledge and understanding of being a parental carer, which could potentially contribute to and develop future services and interventions

**How will my taking part in this study be kept confidential?**

Audio recordings of interviews, electronic transcripts and all associated data/files will be anonymised by assigning each participant a unique participant code. Files will be password protected and stored on a password protected laptop. If it is necessary to place any electronic information on memory sticks, an encrypted memory stick will be used and the files will also be password protected. A back up will be stored on a password protected external hard drive. Only the principle investigator will have access to the unique codes assigned to participants and the passwords to access the laptop and transcribed interviews.

**What will happen to the data collected within this study?**

The data will be anonymised prior to storage. Personal data and consent forms will be stored in a lockable cabinet at the principle investigator's home. The audio recorded interviews and the transcriptions will be password protected and stored on a password protected laptop at the principle investigator's home. The interviews will be transcribed then analysed using a method called Interpretative Phenomenological Analysis.

At the end of the study, all data will be stored at the University of Hertfordshire, in a lockable cabinet, for up to five years for the purpose of publication. After this time, it will be destroyed under secure conditions.

**Who has reviewed this study?**

This study has been reviewed by my supervisor Dr Saskia Keville and The University of Hertfordshire Health and Human Sciences Ethics Committee with Delegated Authority. The UH protocol number is Protocol number: aLMS/PGR/UH/02801 (2).

**Factors that might put others at risk**

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities.

**Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, by email or by phone: [b.s.sharma@herts.ac.uk](mailto:b.s.sharma@herts.ac.uk) or mobile number: 07852280338.

Furthermore, if you would like to get in touch with my supervisor, the details are: Dr Saskia Keville, Clinical Psychologist, [s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk) or contact number: 01707 284232/01707 286322.

**Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar.**

**Thank you very much for reading this information and giving consideration to taking part in this study.**

**UNIVERSITY OF HERTFORDSHIRE  
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS  
(‘ETHICS COMMITTEE’)**

**FORM EC3  
CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS**

I, the undersigned [*please give your name here, in BLOCK CAPITALS*]

.....  
of [*please give contact details here, sufficient to enable the investigator to get in touch with you, such as a postal or email address*]

.....  
hereby freely agree to take part in the study entitled “Fathers’ experiences of caring for an adult child with psychosis: a qualitative study”.

.....  
(UH Protocol number: aLMS/PGR/UH/02801 (2))

**1** I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

**2** I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

**3** In giving my consent to participate in this study, I understand that voice recording will take place and I have been informed of how this recording will be transmitted.

**4** I have been given information about the risks of my suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to me in the event of this happening, and I have been assured that all such aftercare or support would be provided at no cost to myself.

**5** I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

**7** I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

**8** I have been told that I may at some time in the future be contacted again in connection with this or another study.

Signature of participant.....Date.....

Signature of (principal) investigator.....Date.....

Name of (principal) investigator [*in BLOCK CAPITALS please*]  
.....

## Appendix 8: Non-disclosure, confidentiality agreement for transcription

**NON DISCLOSURE AGREEMENT** made on the 11th day of August 2017 ('Agreement Date') **BETWEEN** :

- (1) dictate2us Ltd of Maple House, Haymarket Street, Bury, BL9 0AR (the 'Company'); and
- (2) Bina Sharma of the University of Hertfordshire (*the client*).

Each a 'Party' and together the 'Parties'.

So that the Parties can evaluate their interest in making appropriate arrangements with each other for possible future collaborations (the 'Purpose'), the Information needs to be disclosed between the Parties. Such disclosure will be made on the following terms:

1. In this Agreement, 'Information' means any commercial, technical and other information and data (of whatever nature and form) proprietary to the Disclosing Party which is directly or indirectly disclosed or made available by or on behalf of the Disclosing Party to the Receiving Party, whether in writing, orally, in drawings, by site visits, by access to computer software or data or in any other manner.
2. The Party disclosing the Information (the 'Disclosing Party') is willing to disclose Information to the other (the 'Receiving Party') provided that the Receiving Party does not disclose the same to any third party nor make use thereof other than for the Purpose.
3. The Receiving Party will, in respect of Information received:
  - 3.1 treat it as strictly confidential;
  - 3.2 not divulge it (in writing or orally) to any third party
  - 3.3 not make use of it except for the Purpose; and
  - 3.4 cease transcription if any employee recognises the identity of the information of the Disclosing Party
4. The obligations in this Agreement will not apply to Information which:
  - 4.1 is public knowledge at the Agreement Date or subsequently becomes public knowledge through no act or failure to act on the part of the Receiving Party;
  - 4.2 the Receiving Party can show by written records was known to it at the time of receipt and is not the subject of any restriction on disclosure imposed by a third party;
  - 4.3 is disclosed to the Receiving Party by a third party without restriction and without breach of this Agreement by the Receiving Party;
  - 4.4 the Receiving Party can show by written records has been independently developed by the Receiving Party;
  - 4.5 is released without restriction by the Disclosing Party to anyone; or
  - 4.6 is disclosed by the Receiving Party with the Disclosing Party's prior written consent.
5. The Parties will procure that their employees will observe the terms and conditions of this Agreement. The Receiving Party will only disclose Information received under this Agreement to those persons who need the Information to perform work related to this Agreement.
6. Disclosure under this Agreement will not constitute or imply the grant of a licence to the Receiving Party for any other use of the Information, nor will it imply any transfer to the Receiving Party of either ownership or copyright in the Information.
7. This Agreement will commence on the Agreement Date and will expire one year thereafter unless renewed by mutual consent in writing or terminated by either Party on thirty (30) days written notice to the other. The obligations and restrictions provided in this Agreement shall survive termination or expiry of the Agreement for a period of 5 (five) years.
8. This Agreement shall be governed by English Law and subject to the jurisdiction of the English Courts.

Signed and approved for on behalf of the Client  
Company

Signed and approved for on behalf of the

Name: Bina Sharma

Name: Daryl Leigh

Date: 06/10/2017

Date: 11/08/2017

*B Sharma*

*D Leigh*

**Appendix 9: Debrief Sheet****Debriefing form**

Thank you for taking part in this study, it is very much appreciated!

This study aimed to explore how fathers of children with psychosis have made sense of their caring experiences.

It is hoped that this research will help us understand the benefits and challenges of being a carer from fathers' perspectives. In addition, this research may help us identify factors that can support fathers in their caring role. Potentially it could also educate clinicians, mental health services and commissioners as to how to involve fathers in the treatment of people with psychosis.

In event that participation in this research has raised any questions or concerns for you, please do not hesitate to get in contact with me, or my supervisor, contact details are just below.

Researcher:

Bina Sharma

Trainee Clinical Psychologist

University of Hertfordshire

[b.s.sharma@herts.ac.uk](mailto:b.s.sharma@herts.ac.uk)

Supervisor:

Dr Saskia Keville

Clinical Psychologist and Academic Tutor

University of Hertfordshire

[s.keville@herts.ac.uk](mailto:s.keville@herts.ac.uk)

## Appendix 10: Interview Schedule

### Interview Schedule

1. What sense do you make of your child's psychosis?

*Prompt: Why do you think your child developed it?*

2. How do you support your child?

3. How has your child's psychosis affected your relationship with them over time?

4. How has caring for your child impacted you in other areas of your life

*Prompts: social, relationships, work*

5. How does being a father affect your caring role?

*Prompts: strengths, responsibilities, how does it help or hinder your role?*

6. In what ways have your past experiences helped or hindered you in your caring role?

7. What has your experience been of professional care for your child?

*Prompts: helpful/unhelpful*

8. What do you think could be done better to help you in supporting your child?

## Appendix 11: Transcript from interview with Leo

Emerging themes

Reflections

	Transcript		
<p>Understanding psychosis is difficult</p> <p>Living with a son who has psychosis is difficult</p>	<p>00:00:02</p> <p>S1</p>	<p>Okay, Leo what sense do you make of Wyatt's psychosis?</p>	<p>He was struggling to make sense of what was happening to his son. 'very, very difficult'</p> <p>Does he feel guilty for trying to logically explain Wyatt's symptoms and telling him that his experiences weren't real – 'wrong thing to do'</p> <p>Leo couldn't 'live with the fact that he believed these things' – unwilling to accept that his son was ill/didn't know how to understand/accept that his son was not well?</p> <p>Over time, Leo has made some sense of it</p>
	<p>00:00:14</p> <p>S2</p>	<p>I don't make any sense of it. It's difficult. It's something I never come across before, so when he first started experiencing these problems, it was very difficult to come to terms of what he was believing and initially because I'm coming from a scientific background, I was trying to- logically trying to explain to him how his thoughts couldn't be real, which was totally the wrong thing to do, but it was very, very difficult to try and live with the fact that he believed these things and to him everything was real, so to start with when he initially became ill, it was very difficult.</p>	
	<p>00:01:13</p> <p>S1</p>	<p>I know you said that you hadn't made any sense of it, but have you been able to make some sense of it now?</p>	
	<p>00:01:20</p> <p>S2</p>	<p>To a degree, yes, yes.</p>	
	<p>00:01:23</p> <p>S1</p>	<p>And what is that, if you can explain in words?</p>	
<p>Understanding psychosis is difficult/on-going process</p> <p>I have to come to an understanding on my own</p>	<p>00:01:29</p> <p>S2</p>	<p>Well I can sort of understand a bit about how he came to believe some of the things he believed, but I mean he is a lot better than he was, and I don't think he has the thoughts as much as he used to, so things are starting to come a little bit easier. But yeah, it's something that's just from my own research and things to try and make sense of it a bit more, trying to understand it a bit better than I suppose really, what I've been trying to do.</p>	<p>He took it upon himself to try and understand his son's psychosis 'from my own research' and how it started</p> <p>He still trying to make sense of it – has a lack of a clear answer been frustrating for him? Has anyone helped him with this?</p>

FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

Psychosis=imbalance Uncertainty	00:02:17 S1	And what understanding have you been able to come to?	
	00:02:22 S2	Well, whether it's an imbalance in his mind or whether it's a chemical imbalance or whether it was something that triggered a like event or something that happened at work that triggered the psychosis, I don't really know, but he does seem a little bit better now, yeah.	His understanding – something 'triggers' psychosis, imbalance in brain Important to him that Wyatt is doing better – why does he need me to know this? Is he worried that I am judging him somehow?
	00:02:48 S1	So you're not sure what caused it?	
	00:02:51 S2	No.	Uncertainty. Still no definite answer just some possible ideas.
Worry about Wyatt when he was growing up	00:02:53 S1	Do you have any ideas about why Wyatt might have developed his psychosis?	
	00:02:58 S2	Well, he's always had a sort of depressive nature and he's always been quite anxious about things, even as a child he had periods of depression when he was doing exams and things like that, and I suppose, out of the three children, he's the one that's really we've worried about probably more than the other two because he has had difficulties, he's got dyslexia as well, which hasn't helped with his learning. But yeah, I can't really say what I think has caused him to- I mean he had lots of pressure where he was living because he wasn't living with us at the time when he became ill, he was living in the north, with his girlfriend's family, and although they're extremely nice people, they are Salvationist and they were quite strict about the way he conducted himself and the philosophy on life was quite restrictive I think, whether he found that oppressive- I think he did find that oppressive actually, and his girlfriend has her own mental problems as well, the girlfriend at the time, and I think that,	Sounds like they always had concerns about Wyatt – aware that he was low in mood, experienced anxiety and had dyslexia. I wonder how he/Wyatt's mother handled this, how they supported him. Does he feel guilty for not doing more to help Wyatt when he was younger? Comparison between Wyatt and his siblings Is he angry with Wyatt's girlfriend's family for treating him this way/not taking Wyatt's symptoms seriously? Does he feel guilty that he wasn't there to support his son/could he

FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

Helpless to support son		together with pressure at work because he was working in a call centre, trying to meet sales targets and things, it's not a job that really suits him, his nature, he's not really a sales person, so I think maybe the	have done things differently – different outcome?
Powerless to support son		culmination of all of these things happening together, tipped him over the edge really. There was also a mutual friend who introduced him to his girlfriend, and he was a very controlling person and very strange controlling nature he had, and some of the things that Wyatt has told us about what he done, and you think, that man's not right, he's obviously trying to manipulate people as if they're all like puppets, all his friends are puppets and he's trying to manipulate them, and you wonder whether well, certainly that didn't help his mental wellbeing.	Was he powerless/helpless to support his son?  'Tipped him over the edge'  Is he angry with this mutual friend? Similar reasons to above?  Leo has formulated an understanding of how his son developed psychosis
	00:05:48 S1	You mentioned the other three children and he was the one that you worried about the most, what's that experience that might be...?	
Being a parent is a learning curve	00:05:59 S2	Yeah. He's the eldest, so with the eldest one, it's a learning curve isn't it with anything, so with the other two, I think we were anxious about him when he was born and when he- he was fine I mean, there's nothing...	Wyatt – oldest of Leo's three children.
Being a first-time parent is anxious provoking		but I mean, being new parents, the first child, you always worried about I suppose, because making sure that they're doing the right things at the	His parenting style changed for other children – learnt from experience
Want to get things right		right time and so on, and with the second and third ones, you got that experience, so you're not so concerned about their development and	Parents were anxious too – wanted to do 'the right things at right time'
Want to look out for your children		their progress, so I think that's why I suppose we always were looked out for him more than the others, and he was always quite a nervous child, yeah, he's always a little bit anxious about things so I suppose that was another reason why we looked out for him.	Did they look out for him too much – did this lead to Wyatt's anxiety.
	00:07:01 S1	Is there anything else that you want to add about how you made sense of Wyatt's psychosis, or why you think he developed it?	Leo wants to tell his story of being a good parents and doing all the right things. Is this out of guilt?
	00:07:09	I don't think so, no.	

FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

	S2		
	00:07:10	Okay. How do you support Wyatt?	
	S1		
	00:07:14	How do we support him?	'We' – him and his wife? Sounds like they support Wyatt together
	S2		
	00:07:16	Or how do you specifically support Wyatt?	
	S1		'Main role...taxi service' = very practical role
Paternal carer = practical role	00:07:20	Well mainly, my main role I think is a taxi service, I think that's mainly what I do. His mother has done a lot too - she's a nurse so she understands it probably better than I do, but she's done a lot to try and get him to do things, to try and keep him busy. We haven't had a great deal of help from the team- the occupational health people really haven't helped him at all. He was supposed to have had several interviews with the occupational health people, but they have either cancelled or something has propped up or something else has happened, so it hasn't really happened, so everything that we do for him, when we get him to do, has been self-generated, so for instance, I found an advert for mind, we're running a thing at the local vineyard so I take him there, every Tuesday morning he goes there and he works in the vineyard or he works in the kitchen garden, he does some voluntary work for them, and there's a small team, it's probably about five of them, and they all work together and they do different things and they- it gets him out, something to do outside, he produces food and things and he brings it back you know, vegetables and things, so it keeps him occupied. On a Monday, my wife has found- he's a volunteer at the Hatfield Forest, which is a national trust forest, and he works there on a Monday, so I take him there at 9:00 and I go and collect him in the winter time, half past 3:00, in the summer time it's later, and he works there, he does	Acknowledges wife's role and feels that she has a better understanding of his son's difficulties than him.  He's been let down by NHS, sp. OH. How does he feel by this – angry, disappointed, annoyed?  'Everything we do...has been self-generated' – they've had to do it on their own.  Why do they want to keep him busy? Have they found that helps their son or does it also help them as well?  The way Leo talks here, sounds like he is caring for a young child/teenager:  'keep him occupied'  'I take him there'  'giving him a project'
Frustration with NHS/MH services	S2		
Paternal carer = practical role			
Keeping son busy/occupied is important			

FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

<p>Paternal carer = practical role</p> <p>Keeping son busy/occupied is important</p> <p>Continuous struggle</p> <p>He works really hard to meet son's basic needs = practical</p>	<p>various jobs, mainly sort of litter picking, stuff like that, and helping out with traffic and things like that, so yes, again, <b>that's something he does.</b> He's got a really good friend, he was at school with, his name is Chris and he's got his own car- a business, but he's a mechanic and he fixes cars and Wyatt spends... it has been once a week, he used to go and spend a day with Chris and just helping out, doing bits and pieces for him, not actually getting any pay or anything but <b>just to keep him busy really.</b> The <b>worse time really is at the weekends, it's trying to give him something to do at the weekends,</b> although Piper, she has managed to get him to- into the church choir <b>because he's musical,</b> he did a degree in music technology and he plays the violin and bass and <b>he sings,</b> so he's joined a local church choir. They have a rehearsal on a Thursday evening and serves at most Sunday, <b>so again we found that that helps.</b> We also- because <b>I'm in a band myself and someone in the band is a music therapist, and so we got her coming here once a week for an hour and that's helping him as well because she's giving him a project to try and to do, which again,</b> it's <b>just stuff to keep him busy really, yeah.</b> But other than that, it's <b>just making sure he gets up in the morning, and that's always a struggle,</b> not only- I think using <b>medication doesn't help,</b> that's part of the problem I think, but it's trying to get him moving in the morning and making sure he- <b>I mean he's not very good at personal hygiene, you know, making sure he has a shower</b> and...</p>	<p>'making sure he gets up in the morning'</p> <p>What do they worry will happen if he is not occupied? Does that make him feel like he is a bad parent/not supporting his son properly?</p> <p>They/Wyatt struggles at the weekend</p> <p>Wants to make most of son's abilities/talents/interests</p> <p>In this description about his son, Leo mentions only one thing about himself 'I'm in a band'</p> <p>What's the function of keeping him busy?</p> <p>It's a struggle to get his son to engage in personal care – sounds like he is really disabled by the psychosis</p> <p>Wants his son to be clean/washed and dressed? Is he enforcing what he wants/society expects on his son?</p>
	<p>00:11:53 S1 How is it that you do that?</p>	
	<p>00:11:55 S2 Well, just say, "<b>Look, it's about time you...</b>"</p>	<p>Sounds like he is trying to bring his son to reality??</p>
	<p>00:11:59 So prompting him.</p>	

FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

<p>Keeping son busy/occupied is important</p> <p>Continuous struggle</p> <p>Difficult being a parent/parental carer</p>	<p>S1</p> <p>00:12:00</p> <p>S2</p>	<p>Yes. Prompting him to do it. He belongs to a gym, we got him to go to the gym because another side effect of the medication is weight gain, so again, he doesn't really do much on his own, it's all the time, "Wyatt, do you think you should go to the gym today? Wyatt, are you ready to go because I'm ready to take you?" So I feel like I'm on his back all the time which is unfortunate and...</p>	<p>'we got him to go to the gym' – does his son actually wants to go the gym. Is Leo forcing what he thinks is good for his son onto him – does he have a choice in this? Is that the dilemma the parental carers are continuously grappling with? How does this impact on their emotional wellbeing?</p>
<p>Taking control</p>	<p>00:12:32</p> <p>S1</p>	<p>And how does that feel for you?</p>	<p>Feels 'horrible' but it is coming from a place where he wants his son to be independent – thinking about the future.</p>
<p>Thinking about the future</p> <p>Worry</p>	<p>00:12:33</p> <p>S2</p>	<p>Horrible. I don't like it. I keep saying to him, Look, we're not going to be here forever. At some point, you've got to try and take control and...</p>	<p>Who will look after son when they are not here?</p>
<p>Thinking about the future</p> <p>Uncertainty</p>	<p>00:12:44</p> <p>S1</p>	<p>Why is it horrible? Because you have that feeling that you're on his back all the time?</p>	<p>No one else will care for him after we die.</p>
<p>Thinking about the future</p> <p>Uncertainty</p> <p>Moving on</p>	<p>00:12:49</p> <p>S2</p>	<p>Because... I don't know. I just feel that- I know he's ill, but he should- at the age of 34, he should be thinking about... at some point, he's got to move on because we're not going to be here forever. I think that's it really.</p>	<p>'That's it' – there is no other choice apart from him learning to look after himself 'he should be thinking about'</p>
<p>Moving on</p>	<p>00:13:17</p> <p>S1</p>	<p>So you would like him to be sort of self-motivated...</p>	<p></p>
<p>Moving on</p>	<p>00:13:21</p> <p>S2</p>	<p>Yes.</p>	<p></p>
<p>Moving on</p>	<p>00:13:22</p> <p>S1</p>	<p>...rather than you and your wife...</p>	<p></p>

FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

	00:13:24 S2	Yes.	
	00:13:25 S1	...having to do it. How else do you support Wyatt, it sounds like you do a lot for him, so kind of taking him to the places he used to go, it sounds like you give him a routine...	
Doing the best he can as a parental carer	00:13:38 S2	We try to.	'we' – in it together
	00:13:39 S1	...prompt him. What about the sort of financial support and emotional support?	Sounds like he is a young child:
Financial support	00:13:48 S2	He's on benefits obviously, and he lives here, we don't- I mean, I think, Piper charges him a nominal amount for housekeeping, but I mean we're feeding him, everything so yes. And everything he does like music technology, we're paying for that and things like that so. And when we- no, we find it difficult to leave him, so he comes with us wherever we go, so unless he's actually doing something with somebody else, we don't like leaving him alone so we will take him if we go out somewhere, shopping or... so anywhere else we'll take him with us so yeah.	'we're feeding him' 'we find it difficult to leave him'
Meeting his basic needs			Why don't they like leaving him alone – what are they worried will happen? Relapse/harm himself/suicide attempt – is this influenced by earlier experiences?
Worry			Does having an adult child with psychosis – revert them from an adult to a child?
Keeping him busy/occupied is important	00:14:36 S1	And what about the kind of emotional support?	What impact does this have on his relationship with his wife? Do they get quality time together?
Impact on relationship with wife	00:14:41 S2	I don't know really. I don't think we give- well don't think I really give any emotional support really. It's more practical. I don't know. I don't know.	Why doesn't he give emotional support? Does he see this as important/not his role/doesn't know how to give this?
Paternal carer = practical support			Uncertainty. 'I don't know'
Uncertainty			

## Appendix 12: Example of clustering themes for Leo

Emergent themes from Leo's interview as they arose

Understanding psychosis is difficult	Uncertainty	Supported his parents
Living with a son who has psychosis is difficult	Self-care	Cared for his mother
Understanding psychosis is difficult/on-going process	Emotional Wellbeing	Balancing multiple demands and responsibility
I have to come to an understanding on my own	Having a purpose	Balancing multiple demands and responsibility
Psychosis=imbalance	Having a focus	Paternal carer – practical role
Uncertainty	Surviving	Son – practical role
Worry about Wyatt when he was growing up	Financial impact Loneliness	Satisfied with professional care for Wyatt
Helpless to support son	Isolation	Shock of going to a high-secure hospital
Powerless to support son	Social isolation	Expectations of MH services/hospitals
Being a parent is a learning curve	Difficult	Positive experience of MH services and professionals
Being a first-time parent is anxious provoking	Lack of connections	Conflicting experiences of staff
Want to get things right	Impact of caring on friendships/socialising	Flexibility
Want to look out for your children	Acceptance from their network	Communication
Paternal carer = practical role	Understanding from people around them	Feeling left out as parents
Frustration with NHS/MH services	Hope	Frustration with MH services
Paternal carer = practical role	Stigma is reducing	Frustration with MH services/communication systems
Keeping son busy/occupied is important	Openness in talking about MH	Flexibility

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

Paternal carer = practical role	Friends are helpful	Inclusion
Keeping son busy/occupied is important	Caring impacts on mood/wellbeing	Positive experience of MH services and professionals
Continuous struggle	Uncertainty	Positive experience of MH services and professionals
He works really hard to meet son's basic needs = practical	Balancing multiple demands and responsibility	Support for him as a paternal carer
Keeping son busy/occupied is important	Supporting the family	Valued support for his son
Continuous struggle	Spending time with family is important to him	Valued support for himself and his wife
Difficult being a parent/parental carer	Caring can be a chore	Being realistic
Taking control	Looking after a baby is enjoyable	Appreciated support that son received from work
Thinking about the future	Close relationship with their only daughter	Uncertainty
Worry	Psychosis impacts the whole family	Crisis
Thinking about the future	Uncertainty	Coping
Uncertainty	Impact on finances	Agitation
Moving on	Can't leave son on his own	Worry
Doing the best he can as a parental carer	Worry	Scared
Financial support	Feels closer to his other children	Emotional impact of being a paternal carer
Meeting his basic needs	Caring impacting on husband-wife relationship	Positive experience of MH services and professionals
Worry	Difficulties tolerating conflict/arguing	Communication

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

Keeping him busy/occupied is important	Coping/managers	Inclusion of parents
Impact on relationship with wife	Importance of counselling for parental carers	Valued Wyatt being kept occupied
Paternal carer = practical support	Self-care	Positive experience of MH services and professionals
Uncertainty	Disappointment	Importance of support for parental carers
Denial	Lack of support for parental carers	Positive experience of MH services and professionals
Struggling to understand	Talking helps	Valuing Wyatt's opinion
Coming to terms/Adjustment	Lack of support for parental carers	Frustration with MH services
Acceptance	Uncertainty	Keeping son busy/occupied is important
Acknowledging reality of son's illness	Always going to be a parent	Support
Emotional impact of son with psychosis/caring	Support children no matter what	Frustration with MH services
Hopelessness/Futility	Responsibility	Values psychological input
Uncertainty Risk of harm from son	Dependency	Pressure on him as paternal carer
Feeling scared	Conflict in being a parental/paternal carer	Keeping Wyatt occupied is important
Feeling under threat	Dependency	Carers' support is important
Difficult to deal with	Boundaries	Positive experience of MH services
Worry	Family bond	Values support for himself and his wife
Upsetting	Want to look out for your children	Carers supporting carers can be helpful
Emotional impact of having a son with		

FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

psychosis/being a parental carer	Uncertainty	Self-help group
Treating son like a child	Worry	Sharing caring experiences
Change in father/son dynamic	Importance of support network	Curious about financial support
Uncertainty	Emotional impact of being a parent AND a carer	Caring has an financial impact on the family
Multiple changes	Emotional impact of being a parent AND a carer	Paternal carer = practical
Lack of father/son relationship	Conflict in being a parental/paternal carer	Importance of carer support
Change in father/son dynamic	Perks/benefits of being a paternal carer	Values having a space where he can talk
Dependency	Perks/benefits of being a paternal carer	Communication
Being realistic	Parental carer can offer a different perspective	Inclusion of parents
Dependency	Resentment	Inclusion of parents
Retirement plans had to change due to caring role	Treating children equally	Positive experiences of MH services and professionals
Caring for dad and son	Being a parent helps you to understand other parents	Importance of support for parental carers
Managing multiple demands and responsibilities	Want to look out for your children	Values having a space where he can talk
Put his life on hold	Treating children equally	
Sacrifice	Balancing multiple demands and responsibility	
	Support children no matter what	
	Brief previous experience of caring	

Clustering of themes for Leo

<b>Initial list of themes (repetitions removed, moving towards clustering):</b>	
Uncertainty	Caring impacting on husband-wife relationship
Being a parent is a learning curve	Support children no matter what
Paternal carer = practical role	Conflict in being a parental/paternal carer
Keeping son busy/occupied is important	Importance of support network
Continuous struggle	Emotional impact of being a parent AND a carer
Change in father/son dynamic	Parental carer can offer a different perspective
Dependency	Positive experience of MH services and professionals
Being realistic	Frustration with MH services/communication systems
Impact of caring on friendships/socialising	Inclusion of parents
Balancing multiple demands and responsibilities	Carers supporting carers is helpful
Spending time with family is important to him	Caring has a financial impact on the family
Psychosis impacts the whole family	Values having a space where he can talk
Feels closer to his other children	

<b>Clustered themes</b>	
<u>Impact of being a parent AND a carer</u> Impact on friendships/social networks Impact of relationship with wife Emotional impact on paternal carer and wider family Financial impact Change in father-son relationship/dynamic Role-reversal Balancing multiple responsibilities and demands  <u>What helps/hinders caring process?</u> Inclusion of parents in Wyatt's care at all stages Having a separate space to talk Sharing caring experiences with professionals/other carers The need for professional support Effective communication Uncertainty	<u>Who's in what caring role</u> Father - Practical support Mother – Emotional support/support family financially Friends/voluntary jobs/choir – learning skills/confidence for independence MH professionals – treat/support Wyatt's MH Other carers – support Leo and Piper  <u>Dependency vs. independency</u> Learning skills to enable independence His hopes for Wyatt

Subordinate Theme	Quotes
<i>Impact of being a parent AND a carer</i>	
Impact on friendships/social networks	<p>we have very little, we don't go out very much now, we don't go away very much...</p> <p>It's not very good. I mean, we don't see friends as often as we would like to. Yeah, it's difficult.</p>
Impact of relationship with wife	<p>between Piper and myself, I think we probably bicker a bit more than we used to, it's been- well that's because I'm at home more (laughs), because when I was out at work or whether that's because Wyatt is the catalyst that, I mean, I don't- she probably finds the same, but if she's having a go at him, I can't stand it.</p> <p>it's probably been putting a strain on the relationship certainly, yeah.</p>
Emotional impact on paternal carer and wider family	<p>periods where I feel quite down</p> <p>sometimes you feel, "Is it ever going to get better?" But I will not know.</p> <p>So I come to terms with it now that it is a long haul, but it does getting me down sometimes</p> <p>you wouldn't lie awake at night perhaps so much if it was a third party. As a child, you're always thinking about their future and thinking how are they going to cope when they get better or if they get better, or when they get better, how are they going to cope, so there's always that thought that you probably wouldn't have if it was somebody that you saw, your neighbour or a friend, you wouldn't think, because they have their own support network, I think that's how you think.</p> <p>At one point, he was dragging us all- Piper and I, he was dragging us around the house because he thought the world was caving in and we're in danger of the house collapsing on us, so he was... and at that point, he got sectioned and he went into hospital</p>
Financial impact	<p>we're paying for that and things like that</p> <p>fortunately, we can survive on the pensions and what we get, so I mean, it's not a massive impact really.</p> <p>that's a financial thing we've got to commit to, to have someone here to look after him, so it's on hold at the</p>

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

	<p>moment,</p> <p>we pay for obviously taking him here, there and everywhere and for any therapy that he gets, but whether there is any support, financial support available, we don't know</p>
Change in father-son relationship/dynamic	<p>he doesn't really do much on his own, it's all the time, "Wyatt, do you think you should go to the gym today? Wyatt, are you ready to go because I'm ready to take you?" So I feel like I'm on his back all the time which is unfortunate</p> <p>It's a dependent relationship</p> <p>It's strong but not for the right reasons I think (laughs). It's strong in that, he is dependent on us, but not because we sort of go off and do things together like I mean, some people, they go to the pub or they go to the football together and things like that, but it's something that I can't really see happening.</p>
Role-reversal	<p>I thought when I retire, I'll be able to spend a bit more time with him, because his knees also have become increasingly weak since he's moved back, but I found what with caring for Wyatt and helping him, my father, it's just would've been impossible to carry on working,</p> <p>Piper is still working but she is planning on retiring next year</p>
Balancing multiple responsibilities and demands	<p>I try and get to visit him once a week, and again, that's the time I have to take out, usually what I do is, I'll drop Wyatt off with his friend and then I'll go and see my father, spend some time with him then I come home, then go and collect Wyatt later, so I try and fit it all in around there. And the other thing we have as well now is that we got a granddaughter, our daughter's got a- had a baby girl last year, she just turned one, and she's back at work, my daughter, so we have our granddaughter on a Tuesday we look after her and she spends the night with us here</p>
<i>What helps/hinders caring process?</i>	
Inclusion of parents in Wyatt's care at all stages	<p>they said, "Okay. We'll keep you informed with what's going on with him. We'll involve you. When we have ward meetings and things, you'll be invited as well." So that was good.</p> <p>both the consultant psychiatrists have been very cooperative with speaking to us about Wyatt's condition as well, either privately or with Wyatt present, and that's always helpful.</p>

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

	<p>we'd say to Victor, can we have quarter an hour with you as well, so we could actually talk to Victor as well, and sometimes we'd all meet together with Wyatt's permission, we'd all have a chat together, so that was good.</p>
<p>Having a separate space to talk</p>	<p>because we have had sessions with the psychologist and she said, "Will it be useful for you and Piper to come and have a session with me as well?" So we said, "Yes, that would be useful." So that was quite good. It's not something they normally do because they normally concentrate on helping the service user.</p> <p>We're not excluded which is good, but I said, it might be useful to have somebody from the team who is separate that could talk to us about how we are feeling and what things we could do, what other things we could do to help him.</p> <p>there was also a therapist assigned to us and the family, and he'd ring us up or we'd go and see him or- he was very, very good. Very good. Very well supported it was</p> <p>it's all about, all focussed around the service user if you like</p> <p>I went to see this chap, and I spent an hour with him, and he said, "I really can't help you." And he said, "I could probably help your son, but I don't think you need counselling, I think you're all right, I think you're okay."</p> <p>it's all right actually because it gave me the opportunity to sort of unload a load of stuff, you know, the way I felt and stuff, and that helped, but no, he said he'd be interested to see the outcome, how Wyatt gets on, but he said as far as anything- help that I needed, he felt that he couldn't offer anymore or that I didn't really need it.</p>
<p>Sharing caring experiences with professionals/other carers</p>	<p>we had our own support worker if you like, for the carers, they don't seem to do that here.</p> <p>we had this chap, who used to phone us up or we used to phone him and say, how we were feeling and stuff like that, and that was really helpful,</p> <p>it's amazing, we've got how many people now, probably about 10 or so people, who've all got relatives, daughters or sons with mental health issues, and we get together once a month and we can have a moan and groan basically</p> <p>it's just a self-help group if you like, but it's really useful</p>
<p>The need for professional support</p>	<p>a chap used to come out and go running with him and take him out to places, it was really, really supportive, and they</p>

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

	<p>supported us as well. It was quite good they had like that, he had his own therapist,</p> <p>I think it's because they all cared and there was lots of thing happening there as well, activities that only people came in and did things</p> <p>the consultants, he was initially- he was with Dr Jones, and she was very good, and then when she retired, he was under the care of another doctor, and he's again, another really good consultant, very caring, both of them, yeah.</p>
Effective communication	<p>One of the weird things was that because he was living with his girlfriend's family, his girlfriend was classed as next to kin rather than us, so she got all the- they would talk to her about stuff, but we were sort of left out of the loop to a certain degree.</p> <p>he had good care there and they used to come and talk to us as well the staff, and it's good,</p> <p>We didn't like that and in fact, we said, this is crazy, we need to know what's going on.</p>
Uncertainty	<p>You think, is there a light at the end of the tunnel...</p>
<i>Who's in what caring role</i>	
Father - Practical support	<p>well don't think I really give any emotional support really. It's more practical.</p> <p>what we do for Wyatt really, just take him here, there, take him to places, sit in a room, talk to doctors and things like that</p> <p>mainly, my main role I think is a taxi service, I think that's mainly what I do.</p> <p>so we will take him if we go out somewhere, shopping or... so anywhere else we'll take him with us so yeah.</p>
Mother – Emotional support/support family financially	<p>His mother has done a lot too - she's a nurse so she understands it probably better than I do, but she's done a lot to try and get him to do things, to try and keep him busy.</p> <p>feeding him</p> <p>find it difficult to leave him, so he comes with us wherever we go, so unless he's actually doing something with</p>

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

	somebody else, we don't like leaving him alone.
Friends/voluntary jobs/choir – learning skills/confidence for independence	<p>He's got a really good friend, he was at school with, his name is Chris and he's got his own car- a business, but he's a mechanic and he fixes cars and Wyatt spends... it has been once a week, he used to go and spend a day with Chris and just helping out, doing bits and pieces for him, not actually getting any pay or anything but just to keep him busy really.</p> <p>she has managed to get him to- into the church choir because he's musical, he did a degree in music technology and he plays the violin and bass and he sings, so he's joined a local church choir.</p> <p>he works in the vineyard or he works in the kitchen garden, he does some voluntary work for them, and there's a small team, it's probably about five of them, and they all work together and they do different things and they- it gets him out, something to do outside, he produces food and things and he brings it back you know, vegetables and things, so it keeps him occupied.</p> <p>he's a volunteer at the Hatfield Forest, which is a national trust forest, and he works there on a Monday</p>
MH professionals – treat/support Wyatt's MH	We haven't had a great deal of help from the team- the occupational health people really haven't helped him at all. He was supposed to have had several interviews with the occupational health people, but they have either cancelled or something has propped up or something else has happened, so it hasn't really happened, so everything that we do for him, when we get him to do, has been self-generated,
Other carers – support Leo and Piper	one of the things that Piper has done is set up that carers group, which- because before that, there was nothing, or there didn't seem to be anything.
<i>Dependency vs. independency</i>	
Learning skills to enable independence	I treat him more like a child now than an adult because of the way he is. I find it difficult to talk to him like an adult because I'm having to say, "Wyatt have you done this? Wyatt have you done that?"
His hopes for Wyatt	<p>he should be thinking about... at some point, he's got to move on because we're not going to be here forever.</p> <p>I'd like to treat him as an adult</p>

## Appendix 13: Superordinate and subordinate themes for individual participants

Victor

1. Who's in what caring role
  - a. Father - Practical support
  - b. Mother – Emotional support
  - c. Friends and family – maintain sense of world outside of hospital
  - d. MH professionals – keep Prue safe
  - e. Medical professionals - Keep Prue alive
2. Influences on care-making decisions?
  - a. Parents' role
  - b. Responsible Clinician's role
  - c. Child's role
  - d. Illness' role
3. What impact does caring have?
  - a. Emotional impact
  - b. Impact on physical health
  - c. Burnout
  - d. Frustrations with mental health services and medical professionals
  - e. Uncertainty
  - f. Conflict between being a parent and a carer
  - g. Feeling blamed as a father
4. What helps/hinders caring process?
  - a. Maintaining cooperation and cohesiveness
  - b. The need for professional support
  - c. Advocating for my child
  - d. Self-care
  - e. Boundaries
  - f. Close r/ship with wife/Support
  - g. Sitting with uncertainty
  - h. Rationalisation
5. Being realistic vs. being idealistic
  - a. Hopelessness/futility
  - b. Honesty

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

- c. Expectations
- d. Quality of life
- e. His hope for Prue
- f. Disconnect

## Leo

- 6. Impact of being a parent AND a carer
  - h. Impact on friendships/social networks
  - i. Impact of relationship with wife
  - j. Emotional impact on paternal carer and wider family
  - k. Financial impact
  - l. Change in father-son relationship/dynamic
  - m. Role-reversal
  - n. Balancing multiple responsibilities and demands
- 7. What helps/hinders caring process?
  - i. Inclusion of parents in Wyatt's care at all stages
  - j. Having a separate space to talk
  - k. Sharing caring experiences with professionals/other carers
  - l. The need for professional support
  - m. Effective communication
  - n. Uncertainty
- 8. Who's in what caring role
  - f. Father - Practical support
  - g. Mother – Emotional support/support family financially
  - h. Friends/voluntary jobs/choir – learning skills/confidence for independence
  - i. MH professionals – treat/support Wyatt's MH
  - j. Other carers – support Leo and Piper
- 9. Dependency vs. independency
  - g. Learning skills to enable independence
  - h. His hopes for Wyatt

Ron

1. Impact of caring role
  - a. Change in father-son relationship
  - b. Impact on husband-wife relationship
  - c. Emotional impact
  - d. Impact on work/career opportunities
  - e. Balancing multiple responsibilities and demands
  - f. Impact on wider family relationships (tension)
2. Dependency vs. independency
  - a. Reliance on medication
  - b. Risk/relapse
  - c. Parents' want to be involved with child's care
  - d. Parents know their children best
  - e. Son being well supported by professionals/services is important
3. What helps/hinders caring process?
  - a. Effective communication
  - b. Support and understanding from father's work
  - c. Respecting son's decisions
  - d. Parents not being taken seriously by MH services
  - e. Carers supporting each other
  - f. The need for professional support
  - g. Acceptance
  - h. Advocating for their son
4. Paternal carer vs. Maternal carer
  - a. Paternal = Practical support
  - b. Paternal = Working/provide financially – less time spend with family
  - c. Paternal = support wife
  - d. Maternal = Hands on caring
  - e. Dovetailing of roles
5. Being realistic vs. being idealistic
  - a. Being a carer never stops
  - b. Loss
  - c. Support child no matter what

Neil

1. Being realistic vs. being idealistic
  - a. Parents are in helplessness position
  - b. Parents left to pick up the pieces/deal with consequences
  - c. Parents just want son to be happy
  - d. Injustice of how people with MH and disabilities are supported
  - e. Accept that parents have limited control
  - f. Hope vs. hopelessness/futility
  - g. MH services are fragile
2. Trying to make sense of why this happened to their son
  - a. Impact of father's difficulties on son
  - b. Feels he is partly to be blamed for son's difficulties
  - c. Guilt as a parent/father
  - d. Sense of responsibility
3. Emotionally close r/ship with son vs. distant
  - a. Father-son time is important to him
  - b. Different relationships with his sons
  - c. Change in father-son relationship
  - d. Shared father-son interests are important
  - e. His sons have had completely different trajectories
  - f. Trying to understand his son
4. Impact of finding out child was first unwell with psychosis
  - a. Shock
  - b. Panic
  - c. Chaos
  - d. Angry with university
  - e. Being scared by/of his son
  - f. Parents blame drug dealers
  - g. Unprepared for their son being ill
  - h. Inpatient wards are frightening
  - i. Loss/grief/bereavement
  - j. It could have been worse
5. Connecting current/past experiences/skills to caring/parental role
  - a. Reflecting on his own strengths/positives/resilience

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

- b. Father's change of career has helped him to understand MH better
- c. Lack of male model/father-figure in his own life
- 6. What impact does caring have?/ Impact of being a parent AND a carer
  - a. Strain on friendships and relationships
  - b. Impact of son's illness/caring in r/ship with wife
  - c. Balancing multiple demands and responsibilities
  - d. Emotional impact of being a carer and a parent
  - e. Lots of ups and downs in being a carer
  - f. Financial impact
  - g. Being a parent never stops
- 7. Sharing caring experiences can be helpful vs. can be a burden
  - a. Good coping skills = less need for carer support groups
  - b. Carers supporting each other is a helpful resource
  - c. Carer involvement – using experience in a positive way
  - d. Worry about other carers = burden
  - e. Acknowledges other carers are worse off than them
  - f. Work can impact on paternal carers accessing support for themselves
- 8. What helps/hinders caring process?
  - a. Being involved in son's care is important/positive
  - b. Teamwork/parents and MH pros working together
  - c. Negotiation skills important as a carer Support at work re being a carer is important
  - d. Being a proactive carer/parent is helpful
  - e. Uncertainty
  - f. Parents doing most of the caring/giving most of the support
  - g. Lack of continuity is frustrating
  - h. Broken communication between services and parents
  - i. Impact of service cutbacks on parents
  - j. Stigma of MH
  - k. People don't understand MH/being a carer – 'close down'
- 9. Paternal vs. maternal carer vs. both
  - a. Father=tough love
  - b. Easier for sons to talk to mums about their private life than dads
  - c. Father = being good role model for children
  - d. Father = Supporting wife too
  - e. Both = Occupational support

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

- f. Guidance/Advice
- g. Practical advice
- h. Emotional support
- i. Parents in it together/team

## Bryan

1. Acceptance vs. struggle
  - a. Trying to make sense of why this happened to their son
  - b. Struggle being a parental carer
  - c. Struggled to accept that his son has an illness, thought it was drugs
  - d. Acceptance allowed compassion and understanding
  - e. Can't make a silk purse out of a pig's ear
2. Work vs. home life
  - a. Being a carer never impacted on his work
  - b. Work was his priority
  - c. Home life came second
  - d. Support from work was important
  - e. His work helped him in caring role
3. Inconsistency vs. luck
  - a. Access to services is down to luck
  - b. Services are hit and miss
  - c. Parents doing MH profs job
  - d. Parents need to advocate for son/complain for things to happen/get services for their child
  - e. Moved from pillar to post
  - f. Lack of continuity
  - g. Lack of communication between services, MH profs and service users
  - h. Little NHS support for parents
  - i. Parents not listened to by MH profs
  - j. Lack of professionalism
4. What comes first – drugs or psychosis
  - a. Influence of drugs on mental health and vice versa
  - b. Impact of drugs on father-son r/ship
  - c. Parents at risk of being harmed by drug dealers

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

- d. Financial impact of having a son using drugs/having psychosis - Father had to pay off drug dealers
- e. Costs to son and family of taking drugs
- 5. Father vs. carer
  - a. It's being a father first rather than a carer
  - b. Father - help as much as you can
  - c. Part of being a parent is making sacrifices
  - d. Prioritising son and younger daughter as they his need support now
  - e. He will do anything for his son
  - f. Unconditional love/support despite the bad things that have happened
  - g. Improved r/ship with son over time
  - h. Can never escape being a parent
  - i. Similarity between father and son in in their PH problems
  - j. Impact of older daughter cutting off contact with them
  - k. Double loss – daughter and son
- 6. Impact of caring
  - a. Impact of caring for son on other siblings/rest of family
  - b. Massive financial impact to family
  - c. Emotional impact of caring
  - d. Impact on r/ship with wife
  - e. Impact on their time - always available on phone for son
  - f. Impact what activities they can do/Impact on interests and plans for retirement
  - g. Curtailed social life and friendships
  - h. Balancing multiple demands and responsibilities
- 7. Paternal carer vs. Maternal carer
  - a. Emotional/guidance/reassurance and practical support
  - b. Support him with basic living skills
  - c. Son has close bond with mother not father
  - d. Wife kept them together
  - e. Wife and him keep an eye on each other/try to look after each other
- 8. Being realistic vs. idealistic
  - a. Parents have to do everything
  - b. Parents are in helpless position
  - c. They just get on with it/being carers/parents
  - d. Services supporting Ken supports the parents
  - e. Dependency vs. independency

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

9. Sharing caring experiences can be helpful vs. can be difficult
  - a. Carers' group/Sharing caring experiences is helpful
  - b. Offering support to other carers is helpful
  - c. Learned a lot from carers' groups
  - d. His friends don't understand MH or being a carer – can't share caring experiences with them

## Paul

1. Experiencing psychosis can change your relationship with child – for better or worse
  - a. Emotional close r/ship with son vs. distant
  - b. Experiencing psychosis can completely change a person
  - c. Psychosis devastating for the family
  - d. What comes first – drugs or psychosis?
  - e. Never ending downward spiral
  - f. Parents never imagining this happening to their children
  - g. Spending time with sons is important
2. Step-father vs. biological father
  - a. Step-father role – no man's land, worries about treading on people's toes
  - b. Supports step-sons no matter what/do anything to keep them safe
  - c. Step-father – weird way of caring for someone
  - d. Sudden change – no children to having three step-sons/ready-made family
  - e. Frustration with biological father
  - f. Dedication to step-son and partner despite not being biological father
  - g. Being a step-father/carer is like a 'big merry go round' - adds another layer of complexity
  - h. Emotional support - Good hug/shoulder to cry on/ Reassurance
  - i. Practical support
  - j. He wants to make life as normal as possible for his step-sons
  - k. Needs to be strong for his partner - keeps past experiences to himself
  - l. Connecting past experiences to caring role – emotional
  - m. Being a parent/parental figure can hinder caring role as you are too emotionally close
3. Sharing child's psychosis or keeping it a secret
  - a. Telling work about his step-son was helpful for his caring role
  - b. Telling family about step-sons' psychosis did not change their r/ships with them
  - c. Sharing experiences with other carers was the most helpful thing

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

- d. Sharing = eases the burden and isolation/aids understanding and empathy
- e. Let more people know about carers' groups - vital resource
- f. Psychosis can bring people together
- g. Keeping son's psychosis a secret due to stigma, shame and feeling like you have failed as a parent
- h. People cannot understand your point of view unless you share what is going on
- 4. Inconsistency vs. luck re MH services
  - a. Including parents in caring planning helps them to support their child in the best way they can
  - b. Services supporting their son/s, supports them
  - c. No one else will support your kids the way you can/do
  - d. When services get it right, it can be life-changing for the service user and their family
  - e. Want child to be safe and looked after
- 5. Impact of caring
  - a. Feeling helpless as a parent
  - b. Hopelessness
  - c. Constant worry
  - d. Uncertainty
  - e. Impact on social life, friendships, other relationships/Cycle of losing friends, making new friends, losing friends
  - f. Impact of caring on PH
  - g. Emotional impact
  - h. Risk of burnout/becoming unwell yourself as a carer

## Patrick

- 1. Personal safety vs. wanting to protect child
  - a. Still wanted to help child despite being physically hurt by son
  - b. Father had to look after his own safety
  - c. Wants son to be looked after vs. he can't be the one to do it
  - d. Risk of violence
  - e. Father was vulnerable
  - f. Dichotomy
  - g. Disappointed that his son can't live with him
- 2. Parents against each other vs. in it together
  - a. Parents were not in it together – have different views/understanding of MH
  - b. Mother did not acknowledging son's difficulties

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

- c. Father being blamed for son's MH difficulties
  - d. Mother not supportive
  - e. Father's ethnicity/mixed race blamed for son's MH difficulties
  - f. Couldn't make sense of mother's position
  - g. Mother jealous of father-son r/ship
  - h. Anger/frustration with son's mother
  - i. Father has been main/sole support for son
  - j. Father took son to services – he listened to son
  - k. He has done it on his own
  - l. Stigma of MH
3. Holistic approach vs. diagnosis/labelling
- a. Labelling someone/diagnosis is unhelpful
  - b. Holistic care is the way to go
  - c. Need a reversal in people's mind-set re MH
  - d. Early intervention is important
  - e. Assisted living would be helpful
  - f. Services should look at things from son's point of view
  - g. People with psychosis need more support/help with daily needs/basic life skills
4. Father vs. carer
- a. Good parent = good carer
  - b. You're a father first, only become a carer because you have to be
  - c. Once you're a parent, you're always a parent
  - d. Son is highest priority over any other r/ship
  - e. Prioritised son over work
  - f. Son's welfare is always on his mind
  - g. Protecting/advocating for son
  - h. Spent a lot of time with his son growing up
  - i. Father-son time important
  - j. Will help wherever/however he can
  - k. Parental instinct
  - l. Determined to meet his responsibilities and obligations as a father
  - m. Paternal link always remains
  - n. Being a carer has been a joy, despite the difficulties
  - o. He did the 'full caring role'
  - p. Coming from broken home gave him determination to be the best father

## FATHERS' EXPERIENCES OF CARING: AN IPA ANALYSIS

- q. Connecting with past experiences
- 5. Impact on being a parent and a carer
  - a. Change in your relationship with child – for better or worse
  - b. Emotional impact of caring - loss/grief/disappointment/guilt
  - c. Balancing multiple demands and responsibilities
  - d. Father's disability has impact on caring role and vice versa
  - e. Caring impacted on his work life
  - f. Caring impacted on his mental health
  - g. Financial implications of being a carer
  - h. Being a carer has put a restriction on his life
  - i. Feels helpless /feels he is not supporting son enough
  - j. Feeling isolated vs. knowing there are other people in similar position to you
- 6. Inconsistency of MH services/caring establishment
  - a. Services supporting son supports him
  - b. Inconsistency/lack of services keep people like his son unwell
  - c. Things could be different if services were better
  - d. Services not listened to him as a father
  - e. Frustration/disappointment with MH services
  - f. Services are not good enough
  - g. Become despairing with MH services over time

<b>Appendix 14: Cross-referencing of themes across the data set</b>
---

Superordinate	Subordinate	Victor	Leo	Ron	Neil	Bryan	Paul	Patrick
Father vs. carer	I'm a father first			X		X		X
	As a father, you would do anything for your child	X	X			X	X	X
	Being a parent can hinder caring role as you are too emotionally close		X				X	
Change in quality of relationship with child	For better or worse	X	X	X	X		X	X
	Protecting child vs. looking after self	X		X			X	X
	Spending quality time with <u>all</u> your children/Shared interests are important	X	X	X	X	X	X	X
To share or not to share	Sharing eases isolation		X	X	X		X	X
	Sharing is risky	X		X	X	X		X
Acceptance is a struggle	A double-edged sword: Feeling helpless	X	X	X	X	X	X	X
	Trying to make sense of why and how this happened to my child	X	X	X	X	X	X	X
	Hope vs. Loss	X	X	X	X	X		
Mental health services: inconsistency vs. luck	When services get it right, it can be life-changing for child and family		X		X	X	X	
	Services supporting child support parents	X				X		X
	We need to advocate for our child to get the help they need	X	X		X	X		X

### Appendix 15: Quality Assurance for current study (Tracy, 2010)

Criteria for quality	Description of the criteria	Evidence for meeting criteria
1. Worthy topic	<p>The topic of the research is:</p> <ul style="list-style-type: none"> <li>- Relevant</li> <li>- Timely</li> <li>- Significant</li> <li>- Interesting</li> </ul>	<ul style="list-style-type: none"> <li>- Only a few studies that are related to research question</li> <li>- Clinically relevant area as so many service users with psychosis are supported by a parent/parents</li> <li>- Liaised with lead clinical psychologist working in the field about relevance of study</li> <li>- Aim to gain an insight into experiences and meaning-making using IPA</li> </ul>
2. Rich rigour	<p>The study uses sufficient, abundant, appropriate and complex:</p> <ul style="list-style-type: none"> <li>- Theoretical constructs</li> <li>- Data and time in the field</li> <li>- Samples</li> <li>- Contexts</li> <li>- Data collection and analysis processes</li> </ul>	<ul style="list-style-type: none"> <li>- Sufficient data to support findings as completed seven in-depth interviews</li> <li>- Demographic information on participants is provided (e.g. age, marital status, time in caring role, hours of care provided per week)</li> <li>- Time in field, data collection and analysis spread over one year</li> <li>- Audit data trail to support findings and research process</li> </ul>
3. Sincerity	<p>The study is characterized by:</p> <ul style="list-style-type: none"> <li>- Self-reflexivity about researchers' values and biases</li> <li>- Transparency about methods and challenges</li> </ul>	<ul style="list-style-type: none"> <li>- The researcher's personal and epistemological position is made clear and explained at the start of the research, in relation to the methodology and exploration of the construction of fathers' caring experiences. This provides the reader with an opportunity to consider the role the researcher's position and values may play in the double hermeneutic of understanding the meaning of participants' accounts.</li> <li>- Comprehensive account of data collection and transparency about data analysis</li> </ul>

		<p>process</p> <ul style="list-style-type: none"> <li>- Keeping a reflective diary, peer group supervision and discussions with research supervisors. This aided reflection on the data and research processes as well we my own sense-making and how I might be influencing the themes emerging from the data.</li> </ul>
4. Credibility	<p>The research is marked by:</p> <ul style="list-style-type: none"> <li>- Thick description, concrete detail, explication of tacit knowledge</li> <li>- Triangulation or crystallisation</li> <li>- Member reflections</li> </ul>	<ul style="list-style-type: none"> <li>- Throughout the results section, descriptions and quotes are provided to back up the researcher's themes and interpretations, demonstrating that they are grounded in participants' words. Additionally, some of the theme titles were direct quotes from participants.</li> <li>- Credibility checks were carried out by the principal supervisor on the first three interviews that were analysed. This was to ensure that the researcher was grounding the initial emerging themes in the participants' words and not become too interpretative.</li> <li>- Keeping a reflective diary, peer group supervision and discussions with research supervisors aided reflection on the data and research processes</li> <li>-Member reflections with supervisor and peer supervision group to ensure a robust analysis of the data.</li> </ul>
5. Resonance	<p>The researcher influences, affects, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> <li>- Aesthetic, evocative representation</li> <li>- Naturalistic generalisations</li> <li>- Transferable findings</li> </ul>	<ul style="list-style-type: none"> <li>- The researcher has made efforts to provide accurate representations of participants' experiences. Part of this involved including and sharing quotes from the transcripts, which reflected and resonated with the emotions of the interviews and themes.</li> <li>- Certain issues or themes from the research could potentially connect with readers and audiences wider than the</li> </ul>

		group that were the focus of the study. For example, issues of loss, grief, blame, responsibility, the difficulties of being a parent, stigma of having a child with mental health problems or some form of disability
6. Significant contribution	<p>The research provides a significant contribution:</p> <ul style="list-style-type: none"> <li>- Conceptually/theoretically</li> <li>- Practically</li> <li>- Morally</li> <li>- Methodologically</li> <li>- Heuristically</li> </ul>	<ul style="list-style-type: none"> <li>- The findings provided a rich and detailed insight into fathers' experiences of caring for a child with psychosis. This contributes to the paucity of literature in this area, which is mainly focussed on mothers' experiences of caring.</li> <li>- This study is a starting point for related research to be carried out as explained in the discussion section.</li> <li>- It is also has applications for clinical practice in terms of changing services and mental health professionals' perceptions of fathers and their involvement in the care of their child.</li> </ul>
7. Ethics	<p>The research considers:</p> <ul style="list-style-type: none"> <li>- Procedural ethics (such as human subjects)</li> <li>- Situational and culturally specific ethics</li> <li>- Relational ethics</li> <li>- Exiting ethics (leaving the scene and sharing the research)</li> </ul>	<ul style="list-style-type: none"> <li>- Applied for and was granted UH ethics</li> <li>- Careful consideration was given to the potential distress or emotional reactions for clients during interviews. A pilot interview was conducted with one of the aims being to get some feedback on the emotional impact of being asked and answering the questions in the interview schedule. A debrief was also given at the end of interviews along with information for access to support.</li> <li>- Keeping a reflective diary, peer group supervision and discussions with research supervisors aided reflection on the data and research processes</li> <li>- Ethical considerations were responded to as they arose in the field and during the study</li> </ul>
8. Meaningful	The study:	- The method section clearly outlines how

coherence	<ul style="list-style-type: none"> <li>- Achieves what it purports to be about</li> <li>- Uses methods and procedures that fit its stated goals</li> <li>- Meaningfully interconnects literature, research questions, findings and interpretations with each other</li> </ul>	<p>the appropriateness of the methodology in addressing the research question. Whilst the discussion section explicitly states how the results meet/answer the research question.</p> <p>- The results section presents the integration of ideas across the seven interviews, which allowed the researcher to develop the superordinate and subordinate themes. At the same time, the researcher has strived to present and highlight the nuances of each interview, showing awareness of showing difference and divergence in the data (Smith et al., 2009)</p>
-----------	---	--

## **Appendix 16: Reflective Diary Extracts**

### Reflections following interview with Victor

I was really nervous prior to this interview as it was the first one. I was worried about asking the questions and pace. However, this quickly dissipated as we commenced the interview as Victor seemed relaxed.

...I felt sorry for him. I really wondered about what journey him and his wife have to go through to come to the conclusion that it would be better for their daughter if she passed away. At the same time, I was really surprised by how well he was coping in such on-going, uncertain difficult circumstances. I wonder if this reflected my own assumptions of how stressed or overwhelmed I expected carers to be, prior to the interviews. Does having boundaries and looking after himself help with this? Or is it the relationship between him and his wife. I noticed what a good team they make and how well they seem to complement each other. Maybe, it is because of their daughter and the psychosis that they are closer.

### Reflections following interview with Patrick

I was really struck by his dedication to being a father and how intrinsic they seemed to him. It really moved me in the interview, more so than the prior interviews that I had carried out. Perhaps, this connected with me on a personal level relating to experiences with my own father. I wondered if this had been influenced by him being a single parent and having a difficult relationship with his child's mother. I was aware that he was the first and potentially only father from an ethnic minority group and wondered how this played a role in how he talked about his experiences and made sense of them.

### Reflections following analysis of Paul's transcript

It felt unfair that even one of his step-sons had fallen ill, and for it to happen to his second step-son, felt like it must have been a hard-blow for him and the family. His position as a step-father seemed unique and brought a different aspect to the themes and analytic process, in that it was not the biology that was important. This

was a similar feeling to what I experienced when interviewing Patrick, in terms of the uniqueness and nuances of being a father.

I found myself feeling frustrated on his behalf of his experience of mental health services. Even though this was a common thread in the interviews I had analysed so far, it just seemed so ridiculous to have completely contrasting experiences for his step-sons. It made me feel a bit more pressured to do a thorough and good job of analysis and an overall good thesis, as well as feeling a heightened sense of responsibility in disseminating the research so that things could in fact change for these paternal carers.

**Appendix 17: Additional theme added 'In it together'**

This theme 'In it together' was added post-viva as suggested by the examiners. It could be added to the superordinate theme of 'To share or not to share' (section 4.3). It was not included initially due to space limitations and focus on other themes.

This theme reflected the sense of togetherness that six of the seven participants (all except Patrick) felt they had with their partner and mother of their child. This was demonstrated by multiple uses of the term "we" throughout their interviews (as demonstrated in the following quotes) and references to their partners, such as, "my wife and I" (Neil) and "Patty and I" (Victor).

we share the load if you like...she tends to do one thing and I tend to do another. (Ron)

everything that we do for him...we try and help as much as we can.  
(Leo)

But we're there for him so many times a day at the end of the phone so that he knows that we're here (Bryan)

The above quotes highlighted that the participants felt that they were sharing the role of caring for their child with their partners. Additionally, it seemed the fathers were acknowledging the caring role of that their partners, despite the interview questions being specifically directed towards how they supported their child. Perhaps the participants would have felt uncomfortable not including their partners, especially

as it is usually mothers who have contact with services and are more used to having these types of conversations. There was a sense from the participants that they saw themselves as being in a team with their partners.

we felt as though we were doing a lot of the work, we weren't sort of dependent on professional services because we were supporting him really...we asked if we can have some more family therapy because we felt things had sort of flat lined (Neil)

My partner and I try to take them on holidays, we have taken them to concerts, we try and take them out (Paul)

Neil's comment reflected the onus of supporting their child falling to him and his wife to them and that they had spoken to each other about how this felt for them. Despite how stressful this may have been for the couple, there was a sense that he wanted to present a united front to mental health services, which him and his wife may have thought would aid them in getting the additional therapy they were seeking. This may also have been the case for other participants, highlighted by the repetitive use of the word "we". There appeared to be a joint effort between Paul and his partner in spending quality time together as a family outside of the house. The "try" suggested that this may not always be straightforward but that they are still committed in doing this.

I suppose we were looking after each other really. We'd always try to - no matter how the time was bad, we always try to have a laugh.  
(Paul)

we're hard working, we made a life for ourselves...we've got a strong relationship, we managed to get through it (Neil)

There are suggestions in Paul's and Neil's comments alluding to the impact that caring has had on their relationships. However, they also both reflected on how the relationship with their partner has helped them to cope, manage their caring roles and support not only their child with psychosis, but also their other children. Paul referred to using humour to manage difficult times and situations, whereas Neil reflected on the persistence and resilience within his relationship.