The experience of white British fathers providing care to a son or daughter with a diagnosis of psychosis: An exploration of fathers’ accounts of coping

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FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOsis

MRP Empirical Paper Abstract

**Aim:** Given the move towards community-based care and potential changes in attitudes towards men and caring, it was the aim of this study to explore the experiences of fathers caring for and coping with having a son or daughter with psychosis and begin to identify ‘how’ they cope or ‘what helps’ them to cope in this challenging role.

**Method:** A qualitative exploratory design was employed using semi-structured interviews. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA). Participants were six white British fathers who self-identified as providing care to their son/daughter who had experienced a first-episode of psychosis, and were under the care of an early intervention team. All fathers were of working age, with a mean age of 56 years and the identified child was living with them at the time of interview.

**Results:** Results suggest that gender identity and masculinity play some role in these fathers’ understanding of their caring role. Strategies that helped them to cope were identified and themes around men and talking emerged as prominent in interviews.

**Conclusions:** With the literature lacking in focused research around coping in relation to parents caring for children with psychosis, and even less focused on fathers, the current research adds valuable research into this important population. Themes suggest that providing opportunities for fathers to talk about their emotions and encouragement to make use of strategies they find effective will enable these fathers to continue providing care to their son or daughter. Implications for clinical practice are discussed.

**Key words:** Adaptation, Psychological; Caregivers; Fathers; Psychotic Disorders; Qualitative Research
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The experience of white British fathers providing care to a son/daughter with a diagnosis of psychosis: An exploration of fathers’ accounts of coping

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Abstract

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Key words: Adaptation, Psychological; Caregivers; Fathers; Psychotic Disorders; Qualitative Research
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1. Introduction

With the shift away from hospitalisation and towards community-based care for individuals with mental health diagnoses (Magliano et al., 2007), family members are increasingly taking on caring responsibilities (Shah et al., 2010). Between 2001 and 2011, the number of unpaid carers in England and Wales increased at a faster pace than population growth, with these numbers anticipated to double between 2011 and 2041 (2011 Census, Office for National Statistics (2013)).

1.1 Gender and caring

Historically caregiving has been seen as a feminised role, with many more women than men providing care and the carer role emphasising nurturance, a traditional feminine characteristic (Campbell & Carroll, 2007). Existing research has therefore focused on female carers and the experiences of men caring for someone experiencing psychosis remain relatively unexplored (Sharma et al., 2016; Sin et al., 2005). In a report by the Carers Trust, around half of male carers felt that their needs were different to those of female carers (Slack & Fraser, 2014). This report found 42% of the UK’s unpaid carers to be male, equating to 2.5 million men (Slack & Fraser, 2014). Despite this increase in men entering caring roles and the changing demographics and social norms, family-caregiving continues to be viewed as a feminine activity (Baker & Robertson, 2008). Gender differences have been identified in caring, and it has been suggested that men may experience less stress from the caring role because they adopt a ‘managerial’ approach to caring, avoid being consumed by their emotions and experience greater mastery in the role (Russell, 2001; Thompson et al., 2000; Yee & Schulz, 2000).
1.2 Other factors influencing caregiving

A large body of research in dementia caregiving has directly compared the experiences of caregivers from minority ethnic groups living in the West and the native Caucasian caregiving population (Chakrabarti, 2013). Evidence from this research has demonstrated that the caregiving experience is in large part determined by culturally-defined values, norms, and roles. Typically, Caucasians provide less direct and informal care than minority caregivers (Tennstedt & Chang, 1998), and several studies report lower burden in various minority ethnic groups over Caucasian (Calderón & Tennstedt, 2008; Connell & Gibson, 1997; Knight et al. 2000; Phillips et al. 2000; Sun et al. 2012). Compared with White caregivers, those from ethnic minority groups seem to have informal support networks which are wider and more robust (Connell & Gibson, 1997; Aranda & Knight, 1997; Valle et al. 2004; Kaufman et al., 2010). This has been linked with low service utilisation and less use of formal services in minority ethnic caregivers (Kosloski et al. 2002; Scharlach et al. 2006).

Although the research into carers of someone with a diagnosis of psychosis is much more limited, evidence suggests that factors such as culture and ethnicity influence an individual’s conceptualization and experience of caring (Chakrabarti, 2013), which may relate to group-specific social representations of illnesses such as schizophrenia and different historical experiences of mental health service involvement across different ethnic communities (Fernando, 1988, 1995; Pilgrim & Rogers, 1999). For example, there is evidence that levels of expressed emotion from relatives towards a family member with schizophrenia vary by culture, with a prevalence of high EE ranging from 8% in rural India to 67% in urban USA (Ohaeri, 2003). Weisman et al. (2005) found that greater family cohesion (self-reported) had a
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protective effect against emotional distress in Latino and African-American family members but not for Anglo-American families. In a study by Lopez et al. (2004), low levels of caregiver warmth significantly predicted relapse in Latino patients, but not in European-American patients.

1.3 Gender, caring and coping

Within the male coping literature, the role of masculinity has long been identified as important for those diagnosed with depression and it is accepted that gender-specific coping styles are adopted in those experiencing both depression (Spendelow, 2015) and anxiety (McLean & Anderson, 2009). Previous studies have found men and women to endorse different coping strategies, as measured by the Strategic Approach to Coping Scale (SACS, Dunahoo et al., 1998; Monnier et al., 1998a, b). Gendered identity or masculinities are also thought to influence the way that men understand, experience and approach the caring role (Calasanti, 2004; Harris, 1993; Hirsch, 1996; Miller & Cafasso, 1992; Russell, 2007) and the male caregiver literature has begun to examine male caregiving in relation to masculine social constructs (Campbell & Martin-Matthews, 2003). Calasanti (2004) theorizes gender relations as pivotal in our understanding of the interaction of men and women in later life and Russell (2007, p. 311) found that caregiving was described by the men in their study as a ‘meaningful combination of management, nurturing, and emotional commitments’. Russell (2007) proposed that men may adopt a style of caregiving which incorporates these three elements, which is consistent with men’s individual gender identities (Hirsch 1996) and does not dismiss care management as cold and uncaring or a gender stereotype (Miller and Cafasso 1992). It also challenges the notion that male caregivers are abnormal, or oddities, and
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demonstrates that caregiving experiences can be considered rich and rewarding (Harris 1993).

1.4 Psychosis research

In a review of 42 studies on burden in those caring for a family member with schizophrenia, Caqueo-Urízar et al. (2014) found the majority of caregivers to be parents (usually mothers), followed by spouses and siblings. A number of other reviews have suggested that most family-caregivers of individuals with schizophrenia are parents and the majority are mothers (Baronet, 1999; Bloch et al., 1995; Chan, 2011; Jenkins & Schumacher, 1999; Ola, 2013; Wancata et al., 2008). However, the number of men providing care for a relative with psychosis is increasing (Awad & Voruganti, 2008; Collings, 2009; Ola, 2013) and little is known about gender differences for carers in the context of psychosis. Evidence suggests that male carers are less likely to seek support than female carers (Baker & Robertson, 2008; Cahill, 2000), with evidence that men do not like to talk about health problems and delay seeking help (White & Banks 2004, White 2006). Public health experts suggest that this can result in poorer health outcomes and additional burden on the healthcare system (European Commission, 2011). In a review of literature of parents caring for children experiencing psychosis, Klages et al. (2017) found only a small number of papers to refer to coping and concluded that further research in this area was warranted.

1.5 Male carers of working age

A first episode of psychosis most commonly occurs between the late teens and late twenties, with more than two thirds of women and three quarters of men experiencing their first episode of psychosis before the age of 35.1 (Kirkbride et al., 2006). Given the average age of onset and carers most often being parents, informal
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caregivers are likely to be of working age. Although the majority of carers in the UK are of working age (2011 Census, ONS (2013)), much of the caring literature reports on the experiences of carers over the age of 65, with only 4 of the 25 studies included in the accompanying literature review exclusively investigating experiences of parents of working age caring for a son or daughter with psychosis. The Carer’s Trust found the impact from the caring role on mental health was greater for men of working age (18-64) than in men aged over 65, irrespective of work status (Slack & Fraser, 2014) and thus the need for further research into this group was highlighted.

It has been suggested that male carers of working age may hold less stereotypic gender-role perspectives (Siyanova-Chanturia et al., 2015) and thus potentially demonstrate more flexibility in the way that they approach or cope with the caring role (Cheng, 2005). Although male carers under 65 in England visit their GP more often than the rest of the male population, their health often remains poor, and they are less likely than male carers over the age of 65 to have a carers’ assessment (Slack & Fraser, 2014). Wintersteen and Rasmussen (1997) also found that fathers coping with the mental illness of an offspring experienced emotional stress, largely unrecognized and unacknowledged by mental health professionals. Thus, for fathers of working age in caring roles, appropriate support and services may not be currently provided or their needs adequately understood.

1.6 Fathers caring for a child diagnosed with psychosis

From the related literature review, it has been suggested that fathers may engage in more distanced caring than mothers (Chesla, 1991; Osborne & Coyle, 2002; Poonnotok et al, 2016) and may use more ‘typical’ male responses (such as dealing with emotions alone), and mothers more typical female responses (such as social coping) (Wintersteen & Rasmussen, 1997). However, the picture is unclear,
The few studies which have investigated fathers’ experiences of caring for a child with psychosis suggest that fathers are involved in prolonged caregiving (Howard, 1998), and their experiences can incorporate unresolved issues and emotions (Howard, 1998; Wintersteen & Rasmussen, 1997), such as denial, shock, shame and guilt (Wintersteen & Rasmussen, 1997; Wiens & Daniluk, 2009). In addition, there is evidence that compared with age-matched peers, fathers caring for a son or daughter with psychosis experience higher levels of depression, lower levels of psychological wellbeing, poorer perceived health, and less marital satisfaction (Ghosh & Greenberg, 2009). These fathers may experience their child’s illness in terms of loss (Nyström & Svensson, 2004; Wiens & Daniluk, 2009). Taken together, this evidence highlights the difficult experiences of fathers caring for a son or daughter with psychosis, the negative impact it can have on outcomes for fathers and thus the need to support them in managing or coping in this context. One study by Wiens and Daniluk, (2009) found that fathers found psychoeducational interventions to disregard the differences between fathers’ and mothers’ experiences due to their standardised approach (Nyström & Svensson, 2004). The literature on dementia caregiving has similarly highlighted the importance of enabling fathers to access services which are considered acceptable (Hayes, 2003; Brown et al., 2007; Gitlin et al., 2003; Pretorius et al., 2009), as well as enabling them to effectively use coping strategies (e.g. Hepburn et al., 2002; Kim et al., 2012; Pretorius et al., 2009). A better understanding of how fathers cope with caring for a son or daughter with psychosis and how best to support them is needed.
1.7 What is coping?

Historically, ‘coping’ has been conceptualised in relation to specific theoretical perspectives, with two of the leading perspectives developed by Lazarus and Folkman (1986), and Pearlin and Schooler (1978, p.3). Lazarus and Folkman (1986) defined coping as the process of responding to stressful events/situations, with Pearlin and Schooler (1978, p.3) defining coping as, ‘any response to external life strains that serves to prevent, avoid, or control emotional distress’. Lazarus and Folkman viewed the processes involved in coping as relatively stable across a range of stressful situations, with these processes influencing an individual’s adaptation and outcomes, including somatic health and psychological symptoms (Folkman et al. 1986).

The number of potential approaches or ‘strategies’ used to cope in response to stressors is endless, and attempts have been made to classify or group them. These have included by purpose, meaning or functional value (Schwarzer & Schwarzer, 1996). Some researchers have chosen to classify coping strategies by two basic dimensions, such as attentive, confrontative (‘approach’) or instrumental coping on one hand, and avoidant, emotional or palliative coping on the other (Krohne, 1993; Suls & Fletcher, 1985 provide overviews).

1.8 Theories of coping

In this study, coping is situated within the framework of Pearlin’s (1989) stress and coping model, as adapted in 1990 for Alzheimer’s caregivers (Pearlin et al., 1990; see figure 1 below). This model explicitly references an individual’s history (including biological factors) as providing variance in how they approach stressful situations. It also considers demographic factors, vulnerability and resilience, and the ways in which an individual attempts to cope with or manage that
stress or situation (which could be considered both emotion- and problem-focused coping). Pearlin et al. (1990) suggest that coping refers to management of three key areas: the situation giving rise to stress; the meaning of the situation such that its threat is reduced; and the stress symptoms that result from the situation. In this way, Pearlin et al. (1990) distinguish between sources of stress in a given situation.

*Figure 1.* Simplified version of Pearlin et al. (1990)’s stress process model conceptualising Alzheimer’s caregivers’ stress.

Pearlin et al. (Pearlin et al., 1990; Pearlin & Aneshensel, 1986; Pearlin & Schooler, 1978) proposed that the efficacy of coping could only be determined via its mediating effects at different points in the stress process.

As well as being specifically tailored to a carer context, Pearlin et al. (1990) make a distinction between sources of stress in a given situation, with coping influencing each of these stages and not being limited to being either emotion- or problem-focused, as seen in Lazarus and Folkman’s Transactional Model of Stress
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and Coping (TMSC). Importantly, there is greater potential within this model for emotion-focused coping to be viewed as beneficial, rather than a strategy only employed when demands exceed resources. Folkman et al.’s (1986) view that coping is dispositional (i.e. that similar strategies are applied to different stressful situations) helps to reduce the complexity of coping and its assessment. However, it also assumes that the situation-specific elements of coping responses only represent a negligible aspect of coping as a whole (Schwarzer & Schwarzer, 1996) and there is evidence that these aspects of a stressful encounter are a key element in the coping response observed (McCrae, 1984).

1.9 Study rationale

This introduction has highlighted gender differences in caregiver experiences, meaning-making, the way in which they provide care and how they respond/cope, which are likely to be influenced by culture, ethnicity and gender identity. Whilst men may experience less stress from the caregiver role due to adopting different approaches to their female counterparts (Russell, 2001; Thompson et al., 2000; Yee & Schulz, 2000), they may also delay help-seeking when needed (White & Banks 2004, White 2006) and younger male carers often experience poor health (Slack & Fraser, 2014). With numbers of male caregivers (typically fathers) increasing for psychosis, and the weight of evidence currently focused on dementia caregiving, further research into this potentially younger demographic of male carers is needed. According to Pearlin’s (1990) ‘caregiver stress process model’, how these men are managing their own stress from the caring role impacts on outcomes, such as depression for fathers. This in turn impacts on their capacity to manage all aspects of their situation. An exploratory study allows an investigation of these intrapsychic stress symptoms in a dynamic way, capturing individuals’ understanding and
experiences. As this area is under-researched, gathering this information through an exploratory interview is most appropriate, as it allows a more nuanced insight into how these factors interplay for fathers.

This paper therefore reports on in-depth explorations of the experiences of white British working age fathers who care for a son or daughter with psychosis. Questions related to what fathers ‘do’, ‘what helps’ or how they ‘manage’ were incorporated in order to explore this in interviews (see Appendix D for interview topic guide).

Interpretative Phenomenological Analysis (IPA) was considered an appropriate methodology, as it seeks to represent participants’ experiences of a given phenomenon and places interviewees as experiential experts (Smith & Osborn, 2003), seeing language as a way of accessing an individual’s cognitions. In the ideographic approach of IPA, each interview is treated as a separate case, allowing individual unique perspectives to be represented and situated within that individual’s context. In this way, interviews are partly directed by participants, thus enabling individuals to share their experiences in their own way. Given that the current project is aimed at understanding fathers’ experiences of a particular phenomenon (i.e. caring for a son/daughter with psychosis), the phenomenological approach provides a good fit. The exploratory nature of the study also fits with an inductive approach, allowing themes to emerge, identified by the researcher, and using reflexivity and credibility checks to ensure credibility of analysis (see Appendices N, O & P). IPA has been successfully applied in other studies with an aim of understanding the experience of parents caring for a son/daughter with psychosis (Osborne & Coyle, 2002; Hickman, 2016).
1.10 Study aim

To explore in depth the experiences of White British fathers of working age caring for a son/daughter diagnosed with psychosis. An emphasis was on exploring how these fathers cope with or manage the emotional impact of the caring role on them as carers in this context.

2. Method

2.1 Design

A qualitative design was employed through exploratory semi-structured interviews, conducted and analysed using IPA (Smith & Osborn, 2003).

2.2 Participants

Participants were six White British biological fathers (mean age = 56 years) providing care to a son/daughter diagnosed with a first-episode of psychosis in the past three years. These six volunteer fathers were from middle-high income households in the South-East of England. At the time of interview, all of the children diagnosed with psychosis (four sons and two daughters) were living at home and were under the care of the Early Intervention in Psychosis team. One father reported current depression and anxiety, managed by his GP. One father had been widowed two years prior to interview and the remaining five were married. Fathers’ mean age was 56 years (range = 50-63) and the mean age of their son/daughter under the early intervention team was 16-34 years. Further demographics are presented in table 1, alongside participant alias names.
Table 1.

Participant Alias Names and Demographic Information

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Alias name</th>
<th>Employment status</th>
<th>Career/ job role now or when working</th>
<th>Years caring for son/daughter (since diagnosis)</th>
<th>Current diagnosis of son/daughter</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>David</td>
<td>Sickness absence</td>
<td>Business analyst</td>
<td>2 years</td>
<td>Bipolar affective disorder</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Had taken early retirement</td>
<td></td>
<td>First-episode of psychosis</td>
</tr>
<tr>
<td>2</td>
<td>Paul</td>
<td>Employed part-time</td>
<td>IT manager</td>
<td>2 years</td>
<td>First-episode of psychosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Schizoaffective disorder</td>
</tr>
<tr>
<td>3</td>
<td>Andrew</td>
<td>Employed part-time</td>
<td>Teacher</td>
<td>1 year</td>
<td>First-episode of psychosis</td>
</tr>
<tr>
<td>4</td>
<td>Mark</td>
<td>Employed full-time</td>
<td>Youth worker and gardener</td>
<td>9 months</td>
<td>First-episode of psychosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Close protection (security) driver</td>
<td></td>
<td>Schizoaffective disorder</td>
</tr>
<tr>
<td>5</td>
<td>John</td>
<td>Employed full-time</td>
<td>Managing director of manufacturing company</td>
<td>3 years</td>
<td>Bipolar affective disorder</td>
</tr>
<tr>
<td>6</td>
<td>Michael</td>
<td>Employed full-time</td>
<td></td>
<td>2 months</td>
<td></td>
</tr>
</tbody>
</table>

Alias names were chosen based on participant age (see table 2). The top six UK boys’ names from 1964 (data from the Office for National Statistics (2014)) were allocated to participants so that names ‘fit’ for this client group.

Two additional fathers initially agreed to participate in the study, but withdrew due to family bereavement or a change in family circumstances, leaving them less available to meet.

2.2.1 Sampling strategy

Within the IPA approach, a reasonably homogeneous sample is sought in order to capture experiences of a particular group experiencing a particular phenomenon. The sample of fathers was therefore narrowed by ethnicity (White
British), as culture and ethnicity are thought to impact on an individual’s conceptualization and experience of caring (Chakrabarti, 2013). This was also a pragmatic choice due to the high proportion of White British families in the geographical area under investigation, therefore allowing a reasonable amount of data for analysis whilst keeping a relatively homogeneous sample. Participants were of working age, as the majority of literature reviewed investigated the experiences of both working age and beyond. Any level of care was included, as the Care Act (Legislation.gov.uk, 2014, p. 10) defines a “carer” as, “an adult who provides or intends to provide care for another adult (an “adult needing care”)

Six participants were recruited through purposive sampling to participate in an in-depth interview. A small sample size of between four and ten is recommended as appropriate for a doctoral research project, allowing each interview to be analysed in a detailed, idiographic, and iterative manner, without being overwhelming (Smith et al., 2009). The sample size was also informed by existing research using IPA to explore individual’s experiences of parents caring for a son/daughter with psychosis (Osborne & Coyle, 2002; Hickman, 2016). Inclusion criteria were White British fathers of working age (18 to 65), with a son or daughter who had experienced a first episode of psychosis within the last 3 years. Participants were included irrespective of employment status. Fathers were excluded where they themselves were being treated for a mental health problem above primary care level, as they may be more vulnerable to distress and therefore risk due to participation.

2.2.2 Recruitment

Recruitment took place through two Early Intervention in Psychosis services in the South East of England. Participants deemed by their child’s care coordinator within this service as sufficiently emotionally stable and low risk to participate in
conversations about their child and their caring role were invited to participate in the study. Information leaflets (Appendix B) were given to potential interviewees via their child’s care coordinator. Participants interested in participating completed a reply slip with their contact details, consenting to be contacted by the researcher. Contact was made providing the full information sheet (Appendix C) and interview topic guide (Appendix D) to potential participants, and to arrange a time to meet for interview (at least 24 hours after providing information). Participants were selected on a first come basis, given that they met the eligibility criteria outlined above.

2.3 Data Collection and Interview Design

All participants opted to conduct interviews in their own home. Individual face-to-face interviews were conducted, facilitated by the interview topic guide (see appendix D), which was made available to participants both prior to and during the interview to allow participants’ time to consider their responses and only share what they were comfortable sharing. The semi-structured interview topic guide consisted of a small number of open-ended questions, used flexibly both in terms of specific language, as well as order of use and was developed according to the research question, and guidance on IPA interview development (Shinebourne, 2011; Smith & Osborn, 2003). Expertise was also sought from my research supervisor and a male carer, identified from a local service user group, with the latter providing particular guidance on appropriateness and clarity of questions. Additional prompt questions were used to maintain focus on the research question during interviews. Interviews were audio recorded for later transcription and analysis.

2.4 Ethical considerations

Fully informed consent was gained from participants at the point of interview (see Appendix E for consent form). This study was granted favourable ethical
approval by the University of Surrey Faculty of Health and Medical Sciences Ethics Committee, Health Research Authority, South Central - Berkshire Research Ethics Committee and was given R & D approval from the local NHS Research and Development department (Appendix F, G, H & I; See Appendix J for further ethical considerations.).

2.5 Data analysis

2.5.1 Interpretative Phenomenological Analysis

IPA techniques were followed according to Smith et al.’s (2009) method (see Appendix K for process of data analysis). Interviews were transcribed clean verbatim (see Appendix K) by the researcher or a transcription company, for which consent was obtained (See Appendix L for confidentiality statement). Transcriptions were initially read and re-read, whilst listening to the audio recording. Emergent themes were identified for each interview chronologically, and then examined to form clusters and hierarchies of similar themes, to produce superordinate and subordinate themes. Illustrative quotes were extracted to represent themes from transcripts. Using an iterative process, data were continually checked for meaning. Themes from each interview were then collated across participants and condensed with the aid of research supervisors, in order to provide a more thorough and synthesised analysis (Hefferon & Gil-Rodriguez, 2011). Attention was paid to nuances or differences both within and between participants, in consideration of potential heterogeneities.

2.4.2 Quality assurance

In line with IPA recommendations from Smith et al. (2009), the study’s credibility and rigour were supported through use of Yardley’s (2000) framework (Appendix M) at all stages. A reflexive diary was kept by the researcher to enhance awareness of personal assumptions and beliefs and to minimise their potential impact.
at all stages of the project. Although objectivity is not sought within IPA, developing transparency of one’s own expectations and assumptions was used to allow the analysis to be evaluated by the reader and possible alternatives considered (Elliott et al., 1999). Findings therefore represent one possible account and interpretation of the data, which aims to be plausible, through grounding in illustrative quotes (Larkin & Thompson, 2012). Examples of self-reflexivity, an audit trail of emergent themes and credibility checks can be found in Appendices N, O and P.

3. Results

3.1 Overview of themes

Through Interpretative Phenomenological Analysis of the six semi-structured interviews, the following master-themes and sub-themes were identified:

Table 3.

Master Themes and Related Sub-themes

<table>
<thead>
<tr>
<th>Master theme</th>
<th>Sub-themes</th>
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<td>Coping responses</td>
<td>On autopilot</td>
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<td></td>
<td>Accepting how things are</td>
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<td></td>
<td>Staying strong and not showing emotions</td>
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<td>Making time for me</td>
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<tr>
<td>Men and talking: rules and exceptions</td>
<td>Men aren’t supposed to talk, but it helps</td>
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<td></td>
<td>Things that help men talk</td>
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</table>

These themes will now be explored and interpreted in a narrative account and illustrated via verbatim interview extracts, paying careful attention to the nuances between participant experiences. The readability of extracts has been improved by making some minor alterations (see Appendix K for further information on alterations).
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

The theme of, ‘coping responses’ reports on the ways that these fathers responded to having a son/daughter with psychosis, focusing on the somewhat reactive responses of working ‘on autopilot’ and ‘accepting how things are’, and proactively managing the emotional aspect of the caring role through ‘staying strong and not showing emotions’ and ‘making time for me’.

The theme of ‘men and talking: rules and exceptions’ revealed a more complex and nuanced picture and is therefore given more discussion. The sub-theme, ‘Men aren’t supposed to talk, but it helps’ explores fathers’ dilemma that they are not ‘supposed’ to talk about their feelings, but that it can be helpful when they do. The sub-theme, ‘things that help men talk’ explores the idea that there are certain situations or factors which facilitate men being able to talk about how they are feeling. This suggests flexibility in relation to masculinity for these fathers, capturing the possibility that coping mechanisms traditionally thought of as ‘feminine’ may also be available to men. Themes are explored with reference to fathers’ particular socio-cultural contexts.

3.2 Coping responses

There are four subthemes captured within the first theme of ‘coping responses’. This theme explores how participants responded to having a son or daughter with psychosis and what they found to be helpful. These strategies are seen as examples of fathers relying on their instincts (‘on autopilot’), accepting the situation/their child’s presentation (‘accepting how things are’), managing the emotional impact of caring for their child (‘staying strong and not showing emotions’), and finding space away from the caring role (‘making time for me’).
3.2.1 On autopilot

Four of the six participants spoke of the chaotic nature of psychosis and feeling that they were swept along by it and ‘just had to get on with it’ rather than having time to choose their responses. Paul said, “But you just felt like it was just rushing-- I felt more like I was being pulled by the process rather than being, you know, managing the process…” Paul’s expression of being ‘pulled’ by the process suggests a lack of control. Fathers typically spoke in this way when discussing the early stages of their child developing psychosis, suggesting that this stage of caring involves not knowing fully what is going on. Mark explained, “I don’t think that you have a lot of choice really. You just have to take things as they come, and do your best with them, that’s all I can say. I don’t always get it right but I certainly try.” The idea that fathers couldn’t explain how they were able to manage in those early days was re-iterated by David, “How do you adapt? I dunno, you just do. Natural stuff, you just, defence mechanisms come in, autopilot.” This lack of knowledge of ‘how’ they managed to cope may reflect the feeling of chaos or confusion during the early stages (indicated in five of the six interviews through reports of confusion regarding the timeline of events), or the idea that it was scary (explicitly mentioned by five participants). When faced with uncertainty or chaos, these fathers reported working ‘on autopilot’ or trusting their instincts, with an emerging experience of not having time to think about their responses.

3.2.2 Accepting how things are

All of the fathers spoke in a way that suggested they had accepted how things were, which for one father was expressed as loss, but for others meant accepting uncertainty over their own and their child’s future or acceptance of an unusual presentation/behaviour.
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

Mark explained accepting what life was like now in light of his son’s diagnosis in the following extract:

Mark: But it's about just coming to terms with it, that's all it is and just carry on with my life as best as I can.

Interviewer: What does coming to terms with it mean?

Mark: Just accepting it. There's not a lot I can do other than support him when he needs it, and that's really it. It isn't a lot, I wish I could do, I wish I could fix it but I can't.

Similarly, John talks about the permanency of his son’s condition:

John: “…Once you understand what it is, there's no magic fix out there and you can't be operated on or stuff like that so--

Interviewer: “It's not like having a broken leg--”

John: “--No, [where] you can fix it. This is permanent until one day he might wake up and go, ‘Eureka,’ you know, ‘I'm going to do this. I'm going to do that,’ but I can't see it.”

The idea that it can’t be fixed also gives a sense that acceptance may simply feel like the only option, with Michael saying, “…It's just a position we're in”.

Although fathers spoke of wanting to ‘fix’ the diagnosis, there is also the sense from Mark’s extract that when this is not possible, emotional support can be given in response to their child’s difficulties.

For Andrew, accepting how things are for his son was particularly challenging, as this meant accepting the loss of his hopes for his son’s future, “I think [my son]’s life has been stolen, not only from him but from us. Where are all the attractive young ladies he should have been bringing home? Where are the grandchildren? It's not going to happen. It's not going to happen. I think you come to
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realize that that's the way it is and that's hard.” Although other fathers spoke about an uncertain future for their child, Andrew’s was the account that most fit with the idea of loss/grief, but again highlights the idea of not feeling he has a choice in the situation.

### 3.2.3 Staying strong and not showing emotions

Another ‘coping response’, this sub-theme was represented in all of the six interviews, with two fathers explicitly talking about needing to ‘stay strong’ for their families. Here fathers talk about staying strong for their families in various contexts, with one father in particular connecting this to masculinity.

Michael spoke about needing to stay strong for his daughter around the psychosis when he said, “Like you said, you've got this little thing that you bring up and you absolutely would give your life for and something like that happens to them. Little bit of you inside dies. But then you've got to be strong, got to be strong, for people.” For Michael, this seemed to represent a more traditional masculine identity of being the ‘strong man’ and he describes himself as, “the homely, strong guy” and, “the archetypal father who absolutely adores [his daughters]”. However, his description also speaks of staying strong due to the intense emotional impact of the situation. Michael was a father to daughters and not sons, which seemed to be important to his identity as the protector and provider of the family. In contrast, Andrew spoke of both him and his wife needing to be strong when he said, “...But I think the thing is to try and survive really, survive by finding strategies that will help you be strong for the bits you need to be strong for. Because we tend to be a bit tag team I suppose because there are times when I've had enough and [my wife] takes over and then she's had enough and I take over.” Here, Andrew is talking of the need for both parents to save their strength for the challenges of caring for their child.
with psychosis. One example is when his son did not believe that his parents were really his parents. “...He looked at me in a, ‘I don't know if I can trust you.’ Do you know what I mean? ‘Who are you anyway?’ That sort of thing. Therein lies the mercurial nature of the thing, I suppose, is that you try and be even-minded and be resilient because you will be tested, profoundly tested, and you need to remain strong for that.” Here Andrew is clearly talking about the need for emotional strength and resilience in response to feeling hurt by what his son might say when psychotic. For both these fathers, there is the sense that they are not trying to dismiss or avoid the difficult emotions, but rather putting on a brave face despite the emotional impact on them.

Two of the fathers explicitly talked about ‘keeping calm’ or not showing their emotions. For David, this relates to advice he has been given in how to respond to his son: “-yeah, well confronting is not the thing, keeping stuff calm, slow down, one thing I do is I get too hyper and ‘aah’, all over the place... don’t stand up, don’t move around, just sit down, keep calm, talk slowly, those are stuff that we’ve been told...”

### 3.2.4 Making time for me

The final aspect of the ‘coping responses’ theme relates to ‘making time for me’, which was reflected in 5 of the 6 interviews. This aspect relates to having interests or activities outside of caring for their child, with some explicitly describing this as ‘getting away’. Typically, these were activities the fathers were already engaged in. This is clearly described by Andrew when he said, “We've got dogs we walk every day and when there's that space, I want the space. I want the space of the open air and I want the space of just not having to think about anything or worry about anything.” During our interview, Paul reflected on why he thought he had not
attended a carer support group when he said, “…I may have possibly thought well, actually do I want to go and spend some of my time that I could spend on me. I've probably made a judgment and said I'm going to actually put my feet up, I'm going to play my guitar or--Because I try and do some things to, you know, that are just for me...” Andrew also spoke about going to work as ‘respite’ from the situation at home and Michael spoke about watching television or going cycling in order to get away, which he saw as being ‘therapeutic’, and Mark said he went swimming for ‘a break’. These four fathers mentioned at least one physical activity that helped them to get space from their caring role.

These descriptions reveal an approach to caring involving reactive and proactive responses, with the reactive responses suggesting fathers’ feelings of having to ‘just get on with it’ and the proactive responses aiming to reduce their child’s or their own distress.

3.3 Men and talking: rules and exceptions

This superordinate theme explores ideas raised by fathers around feeling that they can’t talk to other men, particularly about emotions, whilst acknowledging that there are circumstances in which they are enabled to talk about these subjects. In the sub-theme ‘men aren’t supposed to talk, but it helps’, fathers raise the idea that ‘men don’t talk’, but contradictions are seen when fathers explored their views and experiences that talking is useful. The sub-theme of, ‘things that help men talk’ demonstrates the different situations or contexts in which men feel empowered to talk about how they are feeling.

3.3.1 Men aren’t supposed to talk, but it helps

This sub-theme begins with descriptions from fathers that reinforce the stereotype that ‘men don’t talk’, and that there is a ‘code’ that men use to talk to one
another which tends to keep conversations at surface-level. This theme also identifies how attending a parent support group is generally not appealing to men because that’s not what ‘men do’. However, throughout the interviews fathers share their views and experiences about the benefits of talking.

When David was asked what had helped him to manage the ‘emotional stuff’ in relation to his son’s psychosis, he replied, “Dunno. Kept, bottled it up. Blokes, we don’t talk about it.” This suggests that there is an idea (however strongly it is held) that men just don’t “do talking”. Mark also talks about this and offers a suggestion that men and women are different in this area, “Men don't open up, we just don't. You can't talk about things, women, I'm stereotyping terribly a bit, but women can go out and talk about love or whatever. Men would never do that, you just don't do it. It gets like a taboo thing, you don't talk about that stuff to each other...” This again reinforces the idea that ‘men don’t talk’. Two of the fathers spoke about there being rules for men about talking to one another. In response to being asked whether he would talk to his friends about his son’s psychosis, Mark said, “No. I think men tend not to really talk about that. [laughs] We're quite superficial, really. Sports is what we talk about and how to make things, that sort of thing.” This implies that a deeper, perhaps more emotional conversation is not permitted between white British men. Andrew further explains this ‘rule’ when he says that men, “...do everything by code. Rather than say it, we kind of find a way of saying it, without saying it. Like talking about football or racing, it’s a complete and utter waste of time, but actually it’s a code for something. It's a code for social order, for bonding with other people.” Andrew’s comment that men find a way of saying things, ‘without saying them’ again suggests that the male ‘code’ prevents open discussion.
In relation to attending support groups, there is a general suggestion that they are not useful because they can’t ‘fix things’, which is captured by John’s comment, “...What you gonna do? Go along and talk about it, have a cup of tea and a slice of cake, ain’t gonna change it, is it?” Clearly here John’s focus is around what he can do that will practically help or change things, and that attending the support group had not achieved this aim. Paul and Mark were offered the group but chose not to attend. Two of the fathers who had attended a group spoke about support groups not being helpful, but then reflected that they did gain something from it. An example is given from Andrew’s interview:

**Andrew**: “The problem shared is sometimes a problem halved-- actually, not in this case. A problem shared is just like scratching an itch. It's like moaning about work. It's totally useless thing to do but actually, it makes you feel better.”

**Interviewer**: “Maybe not completely useless if you feel like that?”

**Andrew**: “No, not completely useless. No, not at all.”

This extract seems to suggest that there is a belief held that ‘talking isn’t helpful’, but that when looking back at their experiences of attending a group, a helpful element from the group was identified.

Andrew again highlights this dilemma when he says: “My people at work are fantastic. They understand. I don't talk about it too much and they don't ask me about it. Sometimes I think, "That's not very caring," but other times I'm quite grateful they don’t.” The idea that talking is ‘sometimes’ helpful and sometimes not suggests that these fathers do not hold a black-and-white view of the utility of talking.
3.3.2 Things that help men talk

This sub-theme explores the idea that there are certain situations/people which enable men to be able to talk about their emotions and therefore to gain emotional support through talking.

Firstly, Michael and David talk about being able to talk to their wives. Michael said, “I’m a bottler upper, definitely. [my wife] is not, she’s-- she can get me talking but she's my wife, bless her. She knows what I’m like; she knows that I'll talk to her about it, in the end...” This suggests that either wives can be spoken to because of the intimacy of the relationship, because they initiate these conversations, or simply because they are women and they have an ability to ‘get men talking’.

When talking about speaking to his sister about his son’s condition, Mark said, “Actually I do find it, if I'm honest, I find it easy to talk to women about that stuff, they just seem to listen better than men do...” Mark goes on to say that his sister ‘brought it up’, which fits with a comment from David that he doesn’t, “offer stuff” but can talk about it if asked. In addition, there is the suggestion that the positive response from Mark’s sister in relation to him ‘spilling the beans’ about his son’s psychosis encouraged him to tell her more and led to him ‘keeping her in the loop’ about how things are. This suggests that having a positive experience of sharing with others may reinforce men talking to others about their experiences and how they are feeling.

When asked whether he’d gone to anyone for emotional support, Michael explained, “I've got to be honest. I don't really-- I talk about it to anybody who’ll listen but emotional support...”

This seems to suggest that Michael can speak to anyone about what is going on, but does not consider that he needs ‘emotional support’. It may be that there is a
difference between openly acknowledging the need for emotional support which could be seen as weakness (or otherwise negative), and more generally talking about his situation without asking for help.

As well as feeling able to talk to women more easily than to other men, these fathers indicated that the closeness of the relationship to the other person is significant in whether men feel able to talk about their situation. First, John said that it wasn’t difficult to speak to his work because, “Like I said, I’ve been there 15 years. Everyone at work, they know all these kids, anyway. They've seen them grow up.” This suggests that the closeness of John’s relationship with his work colleagues meant that he could trust them with this sensitive information and, for John at least, telling his work colleagues was talked about in a matter-of-fact way, as if it was just a task to be done as part of caring for his son. Similarly but conversely, Andrew talked about the importance of trust in being able to talk to other men, but that this is not the case for strangers. “I mean, you're okay, you're an independent person, so I’ve bared my soul to you. Why I should, I haven't got a clue ‘cos I don't know you from a hole in the ground, but there you are. If it were another bloke, you would have to feel a great deal of trust in order to do that.” It may also be that my being a woman made it easier for Andrew to share personal details with me, as well as my position as a trainee clinical psychologist and therapist. In fact, all participants mentioned or alluded to the seriousness of their child’s illness, which may have enabled fathers to talk to professionals about their situation in order to get help or information (mentioned by Andrew and John).

4. Discussion
This study aimed to explore how white British fathers caring for a son or daughter with a diagnosis of psychosis in the UK experience their caring role and respond to, or cope with the challenges of that role.

This research is valuable as it contributes to our understanding of the experiences of working age fathers who care for a son or daughter with psychosis, particularly as they relate to specific ways that these fathers reported coping in this context. It also highlights the difficulty most of the fathers experienced in talking about their emotions, with a belief that ‘men don’t talk’, coupled with the importance of having the opportunity to do so, and revealing some ways in which this can be facilitated.

Fathers in this study reported coping through being ‘on autopilot’, ‘staying strong’, ‘accepting how things are’, and ‘making time for me’. In relation to Pearlin’s (1990) model of caregiver coping in the context of Alzheimer’s, these themes can be applied to coping with different aspects of the caring role. Where ‘accepting how things are’ relates to an individual’s management of the meaning of a situation, ‘on autopilot’ relates to the management of the situation itself and ‘staying strong’ and ‘making time for me’ relate to managing the stressful impact of the situation on the individual. This supports the idea that these dimensions of coping are important for fathers caring in the context of psychosis, as well as in dementia care. It also suggests that for men in caring roles, some aspects of coping are the same, despite the different carer contexts and demographic differences, thus supporting Pearlin’s model and adding to coping theory for male carers.

In the early stages of their child’s psychosis, the fathers in this study displayed some confusion over timings and described this time as “scary” and “chaotic”. It may be that the scary and confusing nature of a child developing
psychotic symptoms and associated heightened levels of physiological stress may have contributed to their experience of confusion and feeling that they were running ‘on autopilot’. The theme, ‘on autopilot’ fits with the coping strategy of ‘instinctive action’, described by Hobfoll et al. (1993) in the Strategic Approach to Coping Scale, as both relate to a type of action which is not planned, but automatic. In a study by St-Hilaire et al. (2007), parents with high familial exposure to psychosis were less likely to use this form of coping than controls, which they proposed was due to a lack of confidence in one’s coping abilities. Instinctive action may therefore be adaptive in some circumstances, such as in high stress situations, where its use has been found to be associated with reduced anxiety (Monnier et al., 1998).

Fathers in this study responded with acceptance to their child’s psychosis. Accepting the child’s presentation and accepting uncertainty for the future seemed to be helpful for fathers, and there was evidence that Andrew was earlier on in this process and experiencing his son’s illness as a loss not yet resolved (Davy, 1998). Acceptance has been thought to be helpful to parents coping with caring for a son or daughter with psychosis (Chesla, 1991; Howard, 1998; Knudson & Coyle, 2002). It is also considered an important part of the grieving process (Worden, 1991), which must be completed before other stages of grief and has been indicated as important more generally in the context of adapting to a mental health diagnosis (Bach & Hayes, 2002; Bond & Bunce, 2000).

As reported in previous studies (Blomgren Mannerheim et al., 2016; Nyström & Svensson, 2004; Ryan, 1993; Wintersteen & Rasmussen, 1997), ‘making time for me’ seemed to provide some respite and self-care for the fathers in this study and appeared to be an effective way of managing their own intrapsychic stress symptoms (Pearlin, 1990). In the current study, the emphasis was on fathers
maintaining their own wellbeing whilst remaining involved in the care of their son/daughter. This is in line with previous findings that fathers benefited from engaging in employment and social interests (Ghosh & Greenberg, 2012; Nyström & Svensson, 2004) and receiving emotional support from others (e.g. Pejlert, 2001; Poonnotok, 2016) in relation to their caring role. The theme of ‘staying strong and not showing emotions’ was important for these fathers, and one father spoke about not having been “prepared for this” and recommending that children are taught about emotional resilience for what life throws at them. Evidence from previous studies suggests that fathers may be more likely than women to distance themselves from the caring role (Chesla, 1991; Osborne & Coyle, 2002; Poonnotok et al, 2016), but the present study suggests that these fathers sought to build resilience in order to continue providing care to their ill child. It may be that the fathers in this study reflect a cultural shift in British men taking on less stereotypical male roles and more caring roles. In the UK, public support for a traditional division of gender roles within the workplace and home saw a decline from 1984 to 2012, and this trend is expected to continue (Scott & Clery, 2013). The introduction of shared parental leave further reflects this change in attitude towards gender in informal care, and as previously mentioned in the introduction, 42% of unpaid care in the UK is currently being provided by men (Slack & Fraser, 2014).

In the theme, ‘men aren’t supposed to talk, but it helps’, the idea is raised that men aren’t as good as women at talking about emotions, suggesting a gender role expectation in this area. In addition, in the theme, ‘things that help men talk’ it was suggested that closeness in a relationship, necessity, and the other person being female or a professional enabled or gave permission for men to talk about their emotions. Andrew’s comment that talking in code is a “waste of time” may indicate
a frustration about the current system for men and therefore point towards the possibility of change. Research in dementia has suggested that gender role theory may aid our understanding of the experiences of male carers (Sun et al., 2008) and the role of ‘diversity in masculinities’ has been thought to be important (Russell, 2007), as it looks to move away from traditional or hegemonic masculinity and consider “contradictory meanings and experiences of manhood” (Coltrane, 1994, p. 42). This idea of breaking free from hegemonic masculine ways of communicating is further suggested in the theme, ‘things that help men talk’. Mark’s positive experience of sharing about his son’s diagnosis with his sister may act as reinforcement to do this again. A similar but opposite finding has been observed for men having negative experiences around help-seeking and their subsequent reduced likelihood of seeking help in the future (Brown et al., 2007). Michael’s experiences of not needing emotional support may represent a difficulty in openly acknowledging that he needs emotional support and asking for it. Michael particularly seemed to identify with the traditional male identity of being strong, emotionally controlled and independent (Barbee et al., 1993). As help-seeking involves making oneself vulnerable (Lee, 1997), this may be unacceptable to a traditionally-minded man, who may experience such vulnerability as ‘weakness’, an attribute inconsistent with the traditional masculine identity (Barbee et al., 1993).

Two of the fathers in this study had attended a carers’ support group, with one continuing to go, describing it as an outlet for his frustrations with services. One other father suggested that he might attend a group if it was informative in nature, rather than being seen as a support group. Although there was some variation in experiences with groups for carers, the general feedback was that these fathers would not choose to attend a group like this. Research from dementia care has found that
male carers may experience support groups as being of limited use (Pretorius et al., 2009) and uptake may be low (Brown et al., 2007). Several studies in psychosis research have drawn their male participants from support groups (Knudson & Coyle, 2002; Osborne & Coyle, 2002; Rudge & Morse, 2004; Wintersteen & Rasmussen, 1997) and little is known about how many men in this caring role do not access such groups and why. In the current study fathers specifically spoke about the inability of groups to change their situation, even though they may make you feel better. This may represent an emphasis for most of these fathers on problem-focused coping over emotion-focused coping, which has previously been found in men, compared with women (Lutzky & Knight, 1994; Almberg et al., 1997). This also fits with comments from fathers about wanting to ‘fix’ the diagnosis and speaks of a masculine tradition of being able to ‘fix’ problems without help (Pederson & Vogel, 2007; Wellman & Wortley, 1990). However, as Mark described, when a problem can’t be fixed, his response was to provide emotional support to his son, suggesting that this stereotype may be the default position for some of these fathers, but that it is not their only option in responding to their child’s difficulties.

The data presented suggest that masculine scripts and role socialisation play a role in the way that these fathers framed their experiences and responses to the caring role, with fathers explicitly mentioning some aspects, such as being an “archetypal father” and “men don’t open up”. However, descriptions from fathers were littered with exceptions and nuances, suggesting that they adhere less rigidly to these traditional gender roles than previous studies have suggested (e.g. Chesla, 1991; Howard, 1998; Osborne & Coyle, 2002; Wintersteen & Rasmussen, 1997).
4.1 Clinical and policy implications

This study found a diversity of masculinity, also suggested by Courtenay (2002), rather than a single male way of coping (McKenzie et al., 2018). Fathers tended to react instinctively, experiencing the early days of their child’s illness as chaotic. It may be that at this early stage, information and advice are particularly important, as fathers struggle to navigate their child’s symptoms and diagnosis. Previous studies have found useful sources of information to include friends, family, and professionals (Chen, 2016), self-help groups and education courses (Howard, 1998; Landon, 2016), and books and literature (Howard, 1998). It is proposed that professionals already in contact with fathers, such as those in early intervention teams, offer advice and information early on, which may in turn give these fathers confidence in their abilities and cause their ‘instinctive action’ to become more adaptive. Promoting resilience appeared important for these fathers, and it is recommended that fathers are encouraged to continue using coping strategies that are already effective, such as ‘making time for me’, and prioritising their own health, which have been shown to increase resilience (e.g. Ross et al. 2003). In addition, ‘acceptance’ was found to be helpful. Again, those professionals already in contact with fathers, such as in early intervention services, are likely best placed to promote effective use of coping strategies and acceptance. As suggested in previous studies (e.g. Osborne & Coyle, 2002), grief may be a relevant factor for some fathers and the identification of this, alongside appropriate referral to therapeutic interventions for grief, may help them to move towards a position of acceptance (Worden, 1991). Whilst most fathers here chose not to attend carer groups, these should still be offered as they provide opportunities for fathers to benefit from talking about how they are feeling and meeting those in similar situations to themselves. As support
groups seem to be helpful to different people at different times (e.g. Knudson & Coyle, 2002; Landon, 2016), these should be available as and when needed. There are also implications from these findings about ways in which talking can be promoted, as this was reported as being helpful or useful by most fathers. Results suggest that fathers may be more likely to talk to women, to someone they trust, when it is necessary, and to professionals. Mental health professionals are well-placed to engage fathers in conversations about emotions and how they are coping, as they are both professionals and the context may deem it ‘necessary’ for these fathers to talk. In addition, there was the indication that fathers may not initiate these conversations, but may engage if invited, feeling frustrated with having to adopt the male ‘code’ for talking. It may be that women in these roles are particularly well-placed to ask fathers about their emotions, but it is suggested that clinicians of all genders have a responsibility to ask.

The emphasis on involving carers in their loved one’s mental health care and ensuring they are adequately cared for within their role is a focus of the Care Act (2014). It is further highlighted in the Care Programme Approach used in adult mental health services in the UK, as well as the Triangle of Care (Carers Trust, 2013), launched in 2010, which aims to promote partnership working between service users, their carers and healthcare professionals.

4.2 Strengths and limitations

Interviewees varied with regards to the amount of time spent caring, whether they are in paid employment, their current relationship status and whether they are of the same gender as the adult child they are caring for. Although these differences are likely to impact on fathers’ experiences and understanding of their caring role, using IPA allows each individual perspective to be shared, independent of the other
participants. No attempt will be made to generalize these findings to the broader
caring population, but rather to point towards further areas of potential research and
investigation.

All fathers were white and British, which limits the findings to a particular
cultural context. Although this was a pragmatic choice to ensure that a homogeneous
sample of sufficient number was obtained, it is acknowledged that the population of
the UK is diverse and therefore future research should explore the experiences of
fathers from other cultural contexts within the UK in order to broaden our
understanding of the experiences of fathers more generally (Knudson & Coyle,
2002).

Participants were not excluded by their child’s diagnosis, which introduces
some variability in presentation, illness conceptualisation, and experiences.
However, all participants’ children were under an early intervention team and it is
common for participants not to have received a formal diagnosis or that this may
change over time as further information is available (e.g. around presentation or
response to medication). Therefore, it was deemed appropriate to not limit the
participant pool by diagnosis in order to capture the experiences related to a first
episode of psychosis, as has been done in previous studies (O’Toole et al., 2004;
Tansanken et al., 2011). By being under an early intervention team, all participants’
children had experienced a first episode of psychosis within the last three years, with
length of diagnosis ranging from two months to three years. This again introduces
some variability in experience as a result of the stage of diagnosis, although research
suggests that adjustment to psychosis can fluctuate over time (Tait et al., 2004). This
was also a pragmatic choice based on the potential difficulty in recruiting fathers for
the study.
The sample size in this study was relatively small, but within the guidance from Smith et al. (2009), who suggest a sample of between four and ten participants for a doctoral research project. Again, the phenomenological nature of the analysis allows individual experiences to be captured, which better suits a smaller sample size. Consideration was given to the influence of the researcher’s own expectations and assumptions (see Appendix N), as well as to demonstrating rigour and credibility in the research process (see Appendices O and P).

This paper adds a new insight into the experiences of fathers of working age who care for a son or daughter with psychosis in the UK. It sheds light on how these fathers cope with their situation, how talking is difficult but helpful and ways in which this can be facilitated, potentially enabling these fathers to cope more effectively in future. Given the indicators that male gender identity is changing in the UK and the idea that diversity in masculinity appears to be developing, it is also likely that this picture will become even more nuanced and diverse in future.

4.3 Directions for future research

Future research should investigate experiences of fathers of different ethnicities and cultural backgrounds, given the lack of research in this area and likely differences in experience, meaning-making and coping. In addition, future studies should focus on whether the proposed recommendations for support from professionals helps fathers to cope with their caring role; in particular, whether information and advice in the early stages, opportunities to talk about their emotions, promoting the use of their own coping strategies and self-care, and support in resolving grief and moving to a position of acceptance produce benefits for these fathers.
5. References


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MRP Empirical Paper Appendices

Appendix A: Author guidelines for chosen journal (removed)
Appendix B: Participant invitation letter

Participant Invitation Letter [version 2, 02/05/17]
The experience of White British fathers providing care to a son/daughter with psychosis: An exploration of fathers’ accounts of coping

An interview-based study

Introduction
My name is Suzie Richardson and I am a Trainee Clinical Psychologist at the University of Surrey. As part of my training to become a qualified Clinical Psychologist I am conducting some research. I would like to invite you to take part in my study. If you are interested in participating in my study I will provide you with full information and give you an opportunity for further discussion before you make a decision.

What is the purpose of the study?
There is currently a lack of research exploring the experiences of fathers who support their son/daughter with psychosis. However, the number of men providing care to a family member in the UK is increasing. Because of the lack of research in this area, little is known about how men experience and respond to providing care or support to someone experiencing psychosis. Therefore, my research involves exploring your unique, personal and individual experience of having a son/daughter with a psychosis. I am really interested in what this is like for you and how you manage supporting your son/daughter and having time for yourself.

I hope that the findings of this study will give me an insight into the individual experiences of fathers in this caring role. This deeper understanding can be used to help professionals work more effectively with fathers of a son/daughter with psychosis. Topics discussed in the interview may be useful for informing future research or practice (e.g. changing the way that fathers of a son/daughter with psychosis are understood within the health profession, identifying the best way to support these fathers). This research may help in addressing some of these issues.

Why have I been invited to take part in the study?
You have been invited to take part in this study because you are a father who provides some support/care to a son/daughter experiencing psychosis.

To be eligible to take part in the study, you must meet the following criteria:
Be a father of a son/daughter who has received a diagnosis of psychosis within the last 3 years.
Be White British (because ethnicity and culture influence a person’s experiences and understanding of providing care and of mental health conditions)
Be of working age
Are you receiving mental health care, beyond that often provided by a GP, yourself?
If you are I will not be able to include you because there might be a risk of making things worse by discussing your experiences.
I have read the invitation letter and wish to be contacted by the researcher to find out more and arrange a date to talk about my experiences.

IRAS Project ID: 217790
Contact information

Name:

I wish to be contacted by:

☐ Telephone       ☐ Email       ☐ Post

Preferred Contact Information:

If you have opted to be contacted by telephone, I will send you a text message before I call to check that it is a suitable time.

The best day/time for me to be contacted would be: ...........................................

______________________________________________________________________________

OR

You can get in touch with me, Suzie Richardson, directly using the following email address:

Email address: [redacted]

Please note that this is a research email account and will not be checked daily. For urgent enquiries, please refer to the Early Intervention Service working with your son/daughter.
Appendix C: Participant information sheet

Participant Information Sheet [version 2, 02/05/17]
The experience of White British fathers providing care to a son/daughter with psychosis: An exploration of fathers’ accounts of coping

An interview-based study

Introduction

My name is Suzie Richardson and I am a Trainee Clinical Psychologist at the University of Surrey. As part of my training to become a qualified Clinical Psychologist I am conducting some research. Research is really important to the NHS as it can lead changes which might improve the service. I would like to invite you to take part in my study. Before you decide you need to understand why the research is being done and what it will involve for you. Please take the time to read the following information carefully and ask questions about anything you do not understand. Talk to others about the study if you wish. I have also produced a brief study information sheet which can be passed on to your son or daughter.

What is the purpose of the study?

There is currently a lack of research exploring the experiences of fathers who support their son/daughter with psychosis. However, the number of men providing care to a family member in the UK is increasing. Because of the lack of research in this area, little is known about how men’s experiences of caring or supporting a child experiencing psychosis. Therefore, my research involves exploring your unique, personal and individual experience of having a son/daughter with a psychosis. I am really interested in what this is like for you and how you manage supporting your son/daughter and having time for yourself. If you agree to join the study your participation will be anonymous; your name will not appear in any of the material used when the study is written up.

I hope that the findings of this study will give me an insight into the individual experiences of fathers in this caring role. This deeper understanding can be used to help professionals work more effectively with fathers of a son/daughter with psychosis. Topics discussed in the interview may be useful for informing future research or practice (e.g. changing the way that fathers of a son/daughter with psychosis are understood within the health profession, identifying the best way to support these fathers, including helping them to remain in employment) but we will not know about these issues until this research is completed.

Why have I been invited to take part in the study?

You have been invited to take part in this study because you are a father who provides some support/care to a son/daughter experiencing psychosis.

To be eligible to take part in the study, you must meet the following criteria:
Be a father of a son/daughter who has received a diagnosis of psychosis (or a diagnosis of which psychosis is one element) within the last 3 years.
Be White British (because ethnicity and culture influence a person’s experiences and understanding of providing care)
Be of working age
Up to 10 participants will take part in this study. All participants will be fathers of children who attend the Early Intervention in Psychosis service of

Do I have to take part?

No, you do not have to participate. There will be no adverse consequences in terms of your legal rights if you decide not to participate or withdraw at a later stage. Furthermore a refusal on your part will not affect the care and treatment provided for your son/daughter. You can withdraw your participation until 2 weeks after participating in the interview, without giving a reason. After this point, analyses will have begun and it will no longer be feasible to remove your data from the study. Withdrawing will mean that your interview transcript will not be used in the analysis.

If you withdraw from the study this will mean the following for your participation and data:

Both identifiable (our record of your contact details) and anonymised data will be destroyed. No further data would be collected and all research involving you would cease.

What will my involvement require?

If you agree to take part, I will then ask you to sign a consent form. If you do decide to take part you will be given this information sheet to keep and a copy of your signed consent form. The research will last 6 months but your involvement would only be 60 – 90 minutes. During this time, we will meet for an interview to discuss your experiences of having a son/daughter with psychosis. Our conversation will be recorded so that I can transcribe this later and have a typed copy of what we discussed. A professional transcriber may be used for some of the transcription, but they will sign a confidentiality agreement before having access to any recordings. This is to make sure that they do not share any of the information they hear on the recordings with anyone else.

What will I have to do?

This study involves you attending an interview with me. We can arrange a suitable location such as a room in the University of Surrey or a private room in an Early Intervention in Psychosis service. Alternatively I could meet you at your home. From beginning to end the interview can take between 45-90 minutes and will be recorded on a Dictaphone (audio recording device). We can arrange a second interview if you want more time. Once transcribed, the audio recordings will be destroyed.

Before we begin we will go through some paperwork together; an agenda of topics I am interested in hearing about and a Consent Form to double check you understand what the research is about and that you still want to continue. In the interview we will talk about things like how you feel about having a son/daughter with psychosis, what this looks like in your family and how you respond to the situation/what helps.

Once you have completed the interviews I will not contact you again, unless you ask to be informed of the results of the study.

What will happen to data that I provide?

Research data, in anonymous form, are stored securely for at least 10 years and project data such as your consent form for at least 6 years, in line with the University of Surrey policies. The audio recordings will be destroyed once they are transcribed.

IRAS Project ID: 217790
Personal data (data from which you can be identified) will be handled in accordance with the UK Data Protection Act (1998).

With your consent, to make the most of your participation and support efficient advancements in science, any anonymised data may be used for future research. We cannot tell you at this moment in time what this research will entail or what analyses will be carried out but we can assure you that all appropriate legal, ethical and other approvals will be in place. For practical reasons your consent will not be sought again unless you indicate you wish us to do this. Your data will not be used for commercial purposes.

What are the possible disadvantages or risks of taking part?

It is possible that as a result of discussing your experiences of having a son/daughter with psychosis, you may become distressed. You are able to have a break at any point during the interview, without needing to give a reason, and I may offer for us to take a break if I feel that this is appropriate. If you appear particularly distressed, I may choose to stop the interview and I will explain why I have stopped at the time. If you wish to continue at another date, we can arrange to do so.

At the end of the interview I will provide all participants with contact numbers for support services, as well as my own and my supervisor's details, should you wish to get in touch after the interview.

You will have the option of withdrawing your consent after participation, up until 2 weeks after the interview. After this point, analysis of transcripts will take place and it will no longer be feasible to remove the data. However, every effort will be made to help you feel comfortable in talking about your experiences so that your story can be told.

What are the possible benefits of taking part?

You may not see any immediate change or benefit to yourself, but you will be contributing to an important piece of research that could change the future.

Many people find that talking about their experiences helps them to reflect on those experiences and to feel less alone. Having space to talk with someone about you experiences is often reported as being therapeutic and can provide a sense of ‘being heard’.

In addition, the results of the study will be fed back to those who are interested and this may also be helpful in providing you with an overview of all respondents’ experiences, challenges and coping strategies, which you may find helpful.

What happens when the research study stops?

Research often takes years to complete, by which point you may have forgotten that you participated. Researchers always try to publish their findings in relevant journals so that other professionals working in the field can also learn from their study. These are usually academic journals so the public do not tend to see them. I can send you a summary of the results and a copy of the final research study if you would like, plus copies of any articles where the research is published. This research is due to be completed in April 2018.

Researchers also like to present their findings at meetings or conferences for service users, carers, support groups or academics. All of your information will be confidential and no one will be able to identify you.

What if there is a problem?

Any complaint or concern about any aspect of the way you have been dealt with during the course of the study will be addressed; please contact Suzanna Richardson, Principal Investigator or

IRAS Project ID: 217790
or my Supervisor, Kate Gleeson on [contact details]. Alternatively, contact with the University of Surrey can be made by telephone on [phone number].

You may also contact [Director] who is the Director of Surrey University’s Clinical Doctorate programme. If you wish to file a complaint you can do so using the University of Surrey’s complaints procedure.

The University of Surrey holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you will be eligible to claim compensation. This does not affect your legal rights to seek compensation.

**Will my taking part in the study be kept confidential?**

Yes. Your personal data will be accessed, processed and securely destroyed by Suzanna Richardson, Principal Investigator. Data collected during the study may be looked at by authorised individuals from the University of Surrey, from regulatory authorities or from the [Trust], where it is relevant to your taking part in this research. All will have a duty of confidentiality to you as a participant.

You will not be identified in any reports/publications resulting from this research and those reading them will not know who has contributed to it. With your permission we would like to use anonymous verbatim quotation in reports.

1. In certain exceptional circumstances where you or others may be at significant risk of harm, the researcher may need to report this to an appropriate authority. A clear example would include safeguarding concerns regarding a child.

**Full contact details of researcher and supervisor**

Suzanna Richardson, Trainee Clinical Psychologist
Dr Kate Gleeson, Research Director

**Who is organising and funding the research?**

I am organising the research with my supervisor and co-supervisor from the University of Surrey. This research is funded as part of my training.

**Who has reviewed the project?**

This research has been looked at by an independent group of people, called an Ethics Committee, to protect your interests. This study has been reviewed by and received a favourable ethical opinion from South Central, Berkshire, NHS Research Ethics Committee and the University of Surrey Ethics Committee.

**What if I find the interview distressing and want support?**

Talking about your personal experiences in supporting your son/daughter may cause you some distress. At the end of the interview space will be provided to debrief you and to check in with you to see how you are doing.

Please prioritise your own wellbeing. If during or after taking part you feel that you have been adversely affected by any part of the study, please seek the help of your GP.
Alternatively, please call Samaritans: 08457 90 90 90 (UK)
Or Mind: 0300 123 3393

Thank you for taking the time to read this Information Sheet.

IRAS Project ID: 217790

Page 4 of 4
Appendix D: Interview topic guide

- What has been your experience of having a son/daughter with psychosis?

- How have you responded to having a son/daughter with psychosis? What did you do?

- What helps? What makes it better or easier to manage?

- How do you know when you are managing/coping well?
Appendix E: Consent form

The experience of White British fathers providing care to a son/daughter with psychosis: An exploration of fathers’ accounts of coping

Please initial each box

- I have read and understood the Information Sheet provided [version 2, date 02/05/17]. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do.

- I have been advised about any disadvantages / possible ill-effects on my health and well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

- I agree to comply with the requirements of the study as outlined to me to the best of my abilities.

- I agree for my anonymised data to be used for this study / future research that will have received all relevant legal, professional and ethical approvals.

- I give consent for my interview to be audio recorded

- I give consent to anonymous verbatim quotation being used in reports

- I understand that all project data will be held for at least 6 years and all research data for at least 10 years in accordance with University policy and that my personal data is held and processed in the strictest confidence, and in accordance with the UK Data Protection Act (1998).

- I understand that if I disclose information involving possible serious harm to either myself or others, confidentiality may be breached and the appropriate authorities informed.

- I understand that all data collected during the study may be looked at for monitoring and auditing purposes by authorised individuals from the University of Surrey, or from [insert name], where it is relevant to my taking part in this research. I give permission for these individuals to have access to my research records.

- I understand that a professional transcriber may be used to transcribe some of the interviews. However, any transcriber will sign a confidentiality agreement to ensure that all data from the audio recordings remains confidential.

- I understand that I am free to withdraw from the study up until 2 weeks after the interview has taken place, without needing to justify my decision, without prejudice and without my legal rights being affected. Following my request all data already collected from me and all personal data will be destroyed.

- I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation.

- I request that the researchers contact me to provide me with a brief summary of the results of this study once completed (optional).

IRAS Project ID: 217790

Page 1 of 2

When completed: 1 for participant; 1 for researcher side file
Appendix F: Ethical approval: University of Surrey sponsorship

Mrs Suzanna Richardson
School of Psychology
Faculty of Health and Medical Sciences

17 May 2017

Confirmation of sponsorship by the University of Surrey

Dear Suzanna,

Study title: Fathers’ experiences in caring for a son/daughter with psychosis V1
University of Surrey reference: SP09/17/005/FhM5

I am writing to confirm that the above study has satisfied the requirements of the University of Surrey Research Integrity and Governance Office. We are pleased to confirm that the University of Surrey, as a recognised Sponsor under the Department of Health’s Research Governance Framework for Health and Social Care, agrees to act as a Sponsor for your study on the basis of the documentation listed below:

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Your study does not require review by the University of Surrey Ethics Committee and you have permission from the University of Surrey to commence recruitment once the necessary approvals have been obtained from the relevant Research and Development offices. Should the existing protocol undergo any changes you must complete the self-assessment form to determine whether the requirement for ethical review will change.

Please also ensure that you and your supervisors are familiar and act in accordance with the University of Surrey’s Code on Good Research Practice and the Ethical Principles and Procedures for Teaching and Research.

Yours sincerely,

Andrew McClave  
Clinical Research and Governance Officer

Copy to: Dr Kate Gleeson, Dr Alesia Moulton-Perkins
Appendix G: Ethical approval: Health Research Authority

Mrs Suzanna Richardson  
Trainee Clinical Psychologist  
Email: hra.approval@nhs.net

17 May 2017

Dear Mrs Richardson

Study title: White British Fathers’ experiences in caring for a son/daughter with a diagnosis of psychosis: An exploration of fathers’ accounts of coping
IRAS project ID: 217790
REC reference: 17/SC/0171
Sponsor University of Surrey

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England
The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read Appendix B carefully, in particular the following sections:

- Participating NHS organisations in England – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- Confirmation of capacity and capability - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.
Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g., R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices
The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval
The document “After Ethical Review – guidance for sponsors and investigators”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the After Ethical Review document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope
HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.
User Feedback
The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training
We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/.

Your IRAS project ID is 217790. Please quote this on all correspondence.

Yours sincerely
Joanna Ho
Assessor

Email: hra.approval@nhs.net

Copy to: Mr Ali Ashkury, Sponsor Representative, University of Surrey
Dr Kate Gleeson, Academic Supervisor, University of Surrey
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

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<td>Summary CV for supervisor (student research) [Kate Gleeson CV]</td>
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Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Mr Ali Ashkury
Tel: +44 (0) 1483 683499
Email: RIGO@surrey.ac.uk

<table>
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<td>Sponsor has confirmed that IRAS A78 has been incorrectly completed – this study will not generate any new product/process or intellectual property.</td>
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<td>3.1</td>
<td>Protocol assessment</td>
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<td>4.1</td>
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<td>The Statement of Activities will act as an agreement of an NHS organisation to participate. No other agreement is expected.</td>
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<td>Sponsor indemnity arrangements in place for the management, design and conduct of the study.</td>
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<td>Compliant with Standards</td>
<td>Comments</td>
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<td>Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study</td>
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<td>No application for external funding was made for this study. No funding will be provided to participating NHS organisations as indicated in the Statement of Activities.</td>
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<td>REC Favourable Opinion with conditions issued 21 April 2017; acknowledgement of conditions met issued 13 May 2017</td>
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</tr>
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<td>6.4</td>
<td>Other regulatory approvals and authorisations received</td>
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<td>No comments</td>
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</table>
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is a non-commercial multi-centre study where the participating NHS organisation will undertake all research activities as described in the research application. There is therefore, only one site-type for this study.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England will be expected to formally confirm their capacity and capability to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Local Collaborator has been identified for the participating NHS organisation as listed in the IRAS application.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.
HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Local staff substantively employed by the participating NHS organisation, it is unlikely that letters of access or honorary research contracts will be applicable, except where local network staff employed by another Trust (or University) are involved (and then it is likely that arrangements are already in place).

Where arrangements are not already in place, network staff (or similar) undertaking any of the research activities listed in A18 or A19 of the IRAS form (except for administration of questionnaires or surveys), would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm enhanced DBS checks, including appropriate barred list checks, and occupational health clearance. For research team members only administering questionnaires or surveys, a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.
Appendix H: Ethical approval: South Central – Berkshire Research Ethics Committee

Health Research Authority
South Central - Berkshire Research Ethics Committee
Bristol REC Centre
Whitehall
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 0207 104 8057

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval.

21 April 2017

Mrs Suzanna Richardson
Trainee Clinical Psychologist

Dear Mrs Richardson

Study title: The experience of working-age fathers providing care to a son/daughter with a diagnosis of psychosis: An exploration of fathers’ accounts of coping.

REC reference: 17/SC/0171
IRAS project ID: 217790

The Research Ethics Committee reviewed the above application at the meeting held on 18 April 2017. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.
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Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

The Committee gave a favourable opinion of the application (with additional conditions):

1. Please make the changes to the Invitation Letter (Appendix A), Participant Information Sheet (Appendix B), Easy Read PIS (Appendix C) and Consent Form (Appendix D).
2. Amend the study title to 'White British Fathers' experiences in caring for a son/daughter with psychosis VI'. You do not need to re-submit the documents with this change, a cover letter stating that the documentation with the old title has been updated will suffice.
3. Recommendation: The Committee offers a more informal brief information sheet targeted at children of the research participants. You may use your discretion to decide whether to adopt this version; you can then decide whether to offer both versions to the participating fathers, who, in turn can decide which, if either, version they wish to pass on to their child.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).


Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.
Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

- **Social or scientific value; scientific design and conduct of the study**

  The Committee noted that, strictly speaking ‘data saturation’ was more appropriate in Grounded Theory than IPA – but it concluded that this was not really a matter of ethical concern. Plans to keep a reflective diary were welcomed, commenting that this was a good, possibly essential, practice in IPA.

  The Committee noted that, according to the IRAS form, participants were offered the option to meet in a GP surgery or library; it asked how easy it would be to find a private room in these buildings.

  You replied that as you would be recruiting from a large area it would depend on the area the participant was from. You explained that participants could also be interviewed at their home; you would be observing a lone workers policy.

  The Committee thanked you for the information and asked that the option of meeting at home was included in the PIS but stated that the wider options need not be included. In summary the PIS should provide options to meet in the clinic, the University or the person’s home.

- **Recruitment arrangements and access to health information, and fair participant selection**
The Committee noted that recruitment would be via the Early Intervention Service and restricted to white British males. Participants would be given the choice of either making contact with you themselves or having their contact details passed on. It agreed that it was acceptable to restrict the study to white British males due to the lack of resources to extend to other ethnicities or cultures in the confines of a student project. Furthermore the Committee accepted the need to recruit a reasonably homogenous group for this study given the use of IPA; it questioned, however, whether there might be other confounding variables such as social class, religion and educational background.

You replied that you appreciated that you were only selecting a certain demographic of participants and that there were risks of implied racism. In discussion with the Committee you agreed that the title of the project could be amended to reflect the chosen demographic.

The Committee was content with the response given and asked how those offering the invitation letter would know the nationality of potential participants.

You explained that the information would be listed on the NHS database.

The Committee was satisfied with the response given.

- Informed consent process and the adequacy and completeness of participant information

The Committee commented that the PIS should be amended to ensure it was written clearly. The Committee had previously prepared a tracked change version and agreed that you should be required to adopt it as a condition of the favourable opinion.

The Committee concluded that the invitation letter was not well worded and duplicated material provided in the PIS. It provided a tracked change version of the letter which should be adopted.

- Other general comments

The Committee thanked you for a carefully prepared application. It stated that the chosen area of research was interesting and worthwhile with the potential of filling a significant gap in the literature. Your involvement of service users is exemplary, demonstrating considerable respect and valuing of their role from design to dissemination. Your plans to keep a reflective diary were noted and applauded, an essential element of high quality research deploying IPA and ethically invaluable.

The Committee stated that it was disappointed to see that standard wording had been imposed by either the Sponsor or R&D department, which was not appropriate for the study. It stressed that whilst important to cover certain aspects it should be reviewed in context with each individual study.

The Committee explained that some small administration points would be outlined in the letter.

The Committee thanked the applicant for attending the meeting and the applicants left the meeting. The Committee continued to discuss the application.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.
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Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

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<td>correspondence; [Supportive approval email]</td>
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<tr>
<td>Summary CV for supervisor (student research) [Kate Gleeson CV]</td>
<td>1</td>
<td>15 March 2017</td>
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Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.
User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/SC/0171 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

Mr David Carpenter
Chair

E-mail: rescommittee.southcentral-berkshire@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Mr Ali Ashkury
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

South Central - Berkshire Research Ethics Committee
Attendance at Committee meeting on 18 April 2017

Committee Members:

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<th>Name</th>
<th>Profession</th>
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<tr>
<td>Mr David Carpenter</td>
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<td>Dr Mike Emmanuel</td>
<td>Pharmaceutical Consultant</td>
<td>Yes</td>
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<tr>
<td>Mrs Liz Hunter</td>
<td>Retired Midwife and Clinical Governance Manager</td>
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<tr>
<td>Professor Ron King</td>
<td>Mathematician (Retired) Berkshire contact</td>
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<td>Dr Vandana Luthra</td>
<td>R&amp;D Research Co-ordinator</td>
<td>Yes</td>
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<tr>
<td>Mr Daniel Charles Mace</td>
<td>Retired Corporate Lawyer</td>
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<tr>
<td>Mr Richard Merewood</td>
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<td>Mr Neil Thomas O’Kane</td>
<td>Aviation Safety Consultant</td>
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<td>Dr Joanne Philpot</td>
<td>Consultant Paediatrician</td>
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<tr>
<td>Dr Mike Proven</td>
<td>Coordinator for QA in Research</td>
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<td>Ms Ann Quinn</td>
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<td>Dr Deborah Scholey</td>
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<td>Mr Donald Scott-Collett</td>
<td>Lead Pharmacist for Elderly Care, Neuro-rehabilitation, Dermatology and Clinical Governance</td>
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<td>Dr John Andrew Sutton</td>
<td>Medical Director</td>
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Appendix I: Research and Development approval: Local NHS Research and Development department

02/07/2018


Thu 18/05/2017 11:41

Re: Richardson SJ Mrs (PGR - Psychology)

Dear Suzanna,


The study documents have been reviewed and the study has been given R&D approval.

Please contact me using the contact details below if you require any further information.

Kind regards,

[Signature]
Research Facilitator
Research and Development

This e-mail and any files transmitted with it are confidential and are intended solely for the use of the individual or entity to whom they are addressed. If you are not the intended recipient, you are notified that any use, dissemination or copying of this communication is strictly prohibited. If you have received this e-mail in error please notify the sender and delete it immediately. Any information, statements or opinions contained in this message (including any attachments) are given by the author. They are not given on behalf of the author, unless subsequently confirmed by an individual, other than the author, who is authorised to represent them.

From: [Redacted]
Sent: 17 May 2017 16:23
To: [Redacted]
Subject: Fw: IRAS 217790. Outcome of Application for HRA Approval

Dear Alicja,

Please find attached the confirmation of sponsorship from the University of Surrey, as requested.

Best wishes,

Suzie

Suzanna Richardson
Trainee Clinical Psychologist
Appendix J: Further ethical considerations

Informed consent

All participants were full informed of the purpose and nature of the study, both using the invitation letter and then the more in-depth participant information sheet (see Appendices B & C). These forms clearly explained the requirements of participation, information about how data is stored, potential advantages and risks of participation and their right to decline participation or to withdraw up until the point of analysis. At least 24 hours prior to each interview, participants were sent the full participant information sheet (Appendix C) and interview topic guide (Appendix D), so that they could consider what they were happy to share during the interview and the nature of the questions would not be a surprise. At the start of each interview, the participant information sheet was reviewed by the researcher to confirm that this was fully understood by all participants prior to participation. Consent forms were then provided for participants to read and consent was obtained in writing at the point of interview, providing participants were happy to do so (Appendix E). The consent process was audio recorded and confirmed at the end of each interview to check that this had been maintained.

Confidentiality

Participants were first identified by their son or daughter’s care coordinator (within the early intervention team). Participants’ contact details were only passed to the researcher once consent had been obtained from them to do this. Reassurance was provided that their participation and data would remain confidential and anonymous, with access being limited to the researcher alone. Participants were informed of the transcription process and all consented to external transcription, providing confidentiality was maintained. They were also informed that data would
be anonymised, and may be seen by supervisors for the purposes of data analysis, as well as by representatives of academic and professional bodies should this be required. Participants were informed that their data would be stored securely in line with the Data Protection Act, 1998\textsuperscript{1}. Participants were made aware that where verbatim quotes were used in the empirical paper and journal article, all identifying information about individuals would be removed or anonymised.

**Lone working**

Participants were identified through their son or daughter’s care coordinator within the early intervention service they were under. As such, care coordinators were asked to identify fathers who were considered to be low risk to others. As interviews were held in participants’ homes, the lone working policy for the NHS Trust of the early intervention services was followed. This included informing my research supervisor or partner (whichever was available at the time of interview) of times and locations of interviews and making phone calls/text messages after these had been completed. On one occasion my interview over-ran and my partner phoned to check that I was okay.

**Participant wellbeing**

A ‘check-in’ was conducted at the end of each interview, to provide an opportunity to explore any difficult feelings arising from the interview and to check that participants used support mechanisms if needed. Contact details of support organisations were provided to all participants.

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Appendix K: Process of analysis

Single-case analysis

After initial reading of a transcript (alongside listening to audio recording), the transcript was then re-read and annotations made of initial responses to the text in one margin. These included thoughts about content, connections and associations, or significance. These initial responses were then translated into emergent, higher order themes on a second reading of the transcript and these annotated in the other margin. Emergent themes sought to capture the essence of what had been found in the text, grounded in participants’ actual words.

Identification of emergent themes

Emergent themes were identified iteratively through their relevance to the research question, the level of importance for the participant, and richness of material. Superordinate themes across participants were also identified iteratively. Themes and interpretations were verified by re-checking the transcript to ensure that they reflected participants’ actual descriptions. Themes were dropped where they lacked rich evidence in the transcript or didn’t seem to fit well with the emerging structure.

Alterations made to improve the readability of extracts

Dotted lines within square brackets indicate missing material, which allowed relevant quotes to be included in a manageable way. Information within square brackets signifies added material in order to clarify the participant’s comment. Dotted lines at the beginning or end of an extract indicate that the participant was speaking before or continued afterwards. Where not considered to influence the meaning of the remaining quote, minor hesitations and utterances have been omitted.
Appendix L: Confidentiality statement (for transcription)

Transcriber Confidentiality Agreement
The experience of working-age fathers providing care to a son/daughter with psychosis: An exploration of fathers’ accounts of coping, University of Surrey. This research is being undertaken by Suzanna Richardson, Clinical Psychology Doctoral candidate in the Department of Psychology, University of Surrey. The purpose of the research is to explore fathers’ accounts of caring for a son or daughter with psychosis and coping.

As a transcriber of this research, I understand that I will be hearing recordings of confidential interviews. The information on these recordings has been revealed by interviewees who agreed to participate in this research on the condition that their interviews would remain strictly confidential. I understand that I have a responsibility to honour this confidentially agreement. I agree not to share any information on these recordings, about any party, with anyone except the Researcher of this project. Any violation of this and the terms detailed below would constitute a serious breach of ethical standards and I confirm that I will adhere to the agreement in full.

I, Peter Trebek agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the content of the interviews in any form or format (e.g. WAV files, CDs, transcripts) with anyone other than the Researcher.

2. Keep all research information in any form or format (e.g. WAV files, CDs, transcripts) secure while it is in my possession.

3. Return all research information in any form or format (e.g. WAV files, CDs, transcripts) to the Researcher when I have completed the transcription tasks.

4. After consulting with the Researcher, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher (e.g. CDs, information stored on my computer hard drive).

Transcriber:

Signed: [Signature]
Name: Peter Trebek
On behalf of GoTranscript

2017-09-28 (date)

Researcher: Suzanna Richardson (print name) 28/09/2017 (date)

This study has been reviewed and ethically approved by the NHS Research Ethics Committee (REC)
Appendix M: Demonstrating rigour and credibility: Yardley’s (2000) framework

Sensitivity to context

Sensitivity to the existing theory, literature, and research was demonstrated through the literature review, outlining existing research in the area of parents caring for a child with psychosis. This review highlighted a lack of research in the area of coping for fathers of working age providing care to a son or daughter with psychosis. Sensitivity to the specific socio-cultural context of this study was achieved through the sample description in the method section and references to the fathers’ context in the results, where relevant. Sensitivity towards participants’ experience of sharing their stories and to the material obtained was demonstrated through an empathic, non-judgmental approach and responses from the researcher which aimed to validate the individuals’ experiences. In addition, an in-depth data analysis was employed, in which participants’ individual voices are preserved through the use of verbatim extracts.

Commitment and rigour

Commitment to the research topic was demonstrated by in-depth engagement with the research area. This involved wide reading of published literature in scientific journals, keeping up to date with current affairs in the area (including news stories and public health, policies), and meeting with male carers and those caring for a child with psychosis outside of the research study and service environment. As a beginner in IPA methods, I utilised all opportunities to further my knowledge and experience through teaching and supervision in qualitative and IPA methods. This included attending lectures on IPA as part of my clinical training, as well as additional specialist IPA training workshops offered by the University. I also read
relevant books and articles about the approach and its methodology, and immersed myself in existing IPA literature. These opportunities helped to ensure that interviews were guided by the research question and that interpretations remained grounded in the individuals’ accounts. It also kept in mind the importance of maintaining nuance between participants’ contributions, and thus maintaining the individual perspective in IPA. Support from my research supervisor, who is a specialist in the IPA method, was sought throughout the development, conduct and analysis of my research. This enabled credibility checks of my analysis and interpretation, which informed the development of themes and the resulting narrative story. Credibility checks were achieved through comparison of line-by-line analysis of a section of one of my transcripts with a peer, and presenting an initial map of emergent themes for participants to a group of peers and an IPA expert. I checked the validity of chosen quotes with two peers, who were able to challenge my interpretations and support the development of credible themes. I was also a member of a peer supervision group for qualitative research with other doctoral students and joined an online forum for IPA, which allowed me to stay in touch with others undergoing similar analyses and enabled further consideration of challenges as they arose (e.g. discussions over how best to immerse myself in the data, which led to my listening to the audio recordings alongside reading transcripts in order to maintain a connection with the way in which participants spoke about topics, not just the words used). On occasions where my personal assumptions had influenced the validity of data collection or analysis, discussions with my supervisor helped to reduce this and ensure that the themes more accurately reflected the participants’ actual words. Examples of how my analysis was changed based on these discussions are shown in Appendices O and P.
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

Transparency and coherence

This principle was established through clear descriptions of the research and analysis process in the method section. Transparency regarding the analysis process was demonstrated through an audit trail, showing change and development of themes and interpretations over time (Appendix O). Consideration of self-reflexivity allows transparency over the impact of my personal assumptions and experiences during different stages of the study (see Appendix N). Reading, teaching and regular supervision allowed each stage of the study to remain aligned with the underlying theoretical assumptions of the IPA method.

Impact and importance

The useful applications of this research are considered in the discussion section, with particular attention to the clinical implication of findings.
Appendix N: Self-reflexivity

In IPA, there is an assumption that through words, clients are able to convey something of the phenomenon in question (Smith & Osborn, 2003). In the inductive approach, meaning is derived from the data, which in turn is used to inform current theory and develop knowledge of particular phenomena. However, there is also an underlying assumption that the design, data collection, and analysis will all be influenced at least in part by the beliefs, experiences and assumptions of the researcher, due to interpretations and decisions made at each stage of the study (Eatough & Smith, 2008). In light of this, reflexivity offers a means by which these beliefs and assumptions can be reflected on and through such transparency, the researcher and others can be made aware of and reduce their impact on the research process (Yardley, 2000). I will now outline some of my personal beliefs, experiences and assumptions and reflect on their impact at different points in the research process using a reflexive statement.

Self-reflexive statement

I am a thirty-two year old white British female, currently in my final year of training to become a Clinical Psychologist. Prior to training, I worked as an assistant psychologist in an inpatient mental health ward for working age adults. In this post I worked for the first time with individuals experiencing psychosis, a positive and rewarding experience which developed my interest in this client group, particularly in relation to the significant anxiety often present in this condition. I also became more acutely aware of the need for good working relationships between those providing mental health services and the families and carers of the individuals in

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receipt of those services. I began to appreciate some of the difficulties in this relationship, with some relatives and carers feeling ‘left out’ of the treatment process (sometimes due to issues around confidentiality and information-sharing from professionals to carers), whilst realizing the importance of supporting these family members/carers to effectively support their loved one once they returned home.

During my first year of training I worked in a community service for working age adults and again engaged in therapeutic working with individuals experiencing psychosis and also co-facilitated a carers’ support group for this client group. This again highlighted to me some of the difficulties in the carer experience and the need for support in order for these carers to feel empowered to care for their loved one.

Around the same time, I was developing an interest in systemic thinking and working, having dedicated systemic teaching as part of the training programme and these further supported my ideas of the importance of supporting the system in which individuals exist, not just working with the individual, recognizing that “the problem creates the system” (Hoffman, 1990)³, organizing themselves around the problem in response to it. This led to the view that whilst systems do not create ‘problems’, they play a role in maintaining them and can have an influence by way of improving ‘problems’.

Alongside these ideas, I am influenced by my own position as a theist, which in the past has led to the belief that that there is a single truth that can be known (ontological and epistemological positivism). Over time my experiences have challenged the idea of a ‘single’ truth, and yet I could not accept an ontological idealist view, in which nothing exists outside of what is mentally constructed. As my interest in systemic ideas deepened, I became aware of ideas, such as Gregory

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Bateson famously quoting Korzybski in saying, ‘A map is not the territory it represents, but if correct it has a similar structure to the territory which accounts for its usefulness’ (Korzybski (1933), p. 58). This appealed to my belief that there really is a reality (territory), and that how we describe it (the map) is useful, but not a perfect fit with ‘reality’. I have also been influenced by social constructionist ideas (Burr, 2003), that the way an experience is talked about has an influence over that experience. In wanting to find a ‘home’ for my beliefs, I conducted further reading and stumbled across the theory of ‘critical realism’. This theory combines the idea that a true reality exists, even outside of our experience (Drake, 1925), and although true reality may never be completely understood, observable events reflect an unobservable reality. This also allows the application of scientific research, as it reflects reality enough to be useful (whilst accepting it has limitations) and also allows social constructionist ideas to influence findings, taking a moderate constructionist view that it is only beliefs about reality that are socially constructed, rather than reality itself (Hacking, 1999). This journey has led me to the understanding that there are multiple perspectives about any given experience, including that of caring for a son or daughter with psychosis. A critical realist stance allows social scientific research to illuminate explanations of individual experience, situated within specific time and place, including sociocultural contexts (epistemological relativism, Scambler, 2017). It was my great delight, therefore, to

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discover that IPA has roots in critical realism (Fade, 2004), where differences in the meaning that individuals attach to their experiences represent their experiencing different parts of reality (Fade, 2004). IPA also has roots in the social cognition paradigm, which holds that these meanings can be directly or indirectly derived from human speech and behaviour (Fade, 2004). Therefore, my aim in conducting the current research study was to develop an understanding of the differences in the meaning held for the fathers’ in these interviews.

**Impact of the self at different stages of the study and revisions made**

Examples here demonstrate how my beliefs, experiences, and assumptions influenced the design, conduct and analysis of the study. It also reports on how the study design and analysis were revised, influenced by feedback from my supervisor, ensuring that the study was aligned with IPA and reflected participants’ real worlds.

**Assumptions about fathers’ experiences**

Some of my assumptions about the fathers I interviewed were that they would have experienced challenges in their role and that this would be accessible for them to talk about (although not necessarily easy to do). It was difficult, then, when I encountered a father who did not seem to view his experiences in relation to challenges or difficulties, rather seeing the situation as just another part of his son’s life. It was important for me to suspend my views about there being challenges and to allow this father to tell his story in the way that best fit for him.

**Therapist/researcher role tensions**

As a trainee clinical psychologist I was aware that my main role was as a therapist and that this is a different position to being a researcher, where I would

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need to both lead and follow in order to direct conversation towards my research question. However, I was also conscious that the topic of discussion could cause distress or otherwise be experienced as emotional by participants and completing the ethics application helped me to bring this aspect of the research to mind whilst conducting interviews, rather than seeing it solely as a research exercise, in isolation from my therapeutic role. Indeed, participants were partly held under the Early Intervention team for their child, but not directly under services themselves so it was important (despite their low risk) to manage any concerns or distress raised during interviews. During my first interview I encountered a dilemma when a father became tearful during the interview. I was conscious that in my therapeutic role I might wish to explore emotional content in order to help the client to understand and manage this better, but that in interviews I was not acting as a therapist. I subsequently took the case to a qualitative training session at the university and we explored the importance of empathizing ‘as anyone would’, but not turning interviews into therapy sessions. This was particularly helpful in giving me the confidence to respond at a level which would contain participants, without needing to explore these issues further (unless it pertained to risk). It may be that my position as a therapist or style of interviewing enabled fathers to be more vulnerable about their emotional experiences and potentially provided a space in which fathers could express these parts of their experience without judgment, which may not specifically be given space elsewhere. It strikes me after having completed all my interviews that perhaps I am well-placed to conduct this research, due to my skills as a therapist.

**Power dynamics**

All interviewees chose to be interviewed in their own homes, which potentially helped them to feel in control of the situation and may have acted to
reduce any power imbalance from my being a highly educated, white middle-class professional interviewing them. However, during interviews it was clear that there was some element of fathers viewing me as an ‘expert’ in mental health, and therefore an emphasis on their expertise by experience helped me to maintain a curious stance during interviews (Cecchin, 1987). On the other side, all fathers were white men, older than myself, some at the height of their careers and homeowners (which I became during the interview process), and were also parents, thus holding particular experiential expertise in this area. I was aware of not being a parent, although throughout the course of the research I became pregnant, so this may have impacted on my beliefs and ideas about parenting over the course of the study. It is interesting to note that although I am more similar in age to the children of these fathers, I aligned myself more with the parental position, which may have been due to the lack of a mental health diagnosis, the fact that I was talking directly with fathers and exploring their experiences, or because I was thinking about becoming a parent myself.

**Interview schedule development and data analysis**

In general, prior to interviewing I held beliefs that these fathers might be more involved in caring for their children more generally, potentially holding less stereotypical gender identities and roles than previous studies have found, due to societal and cultural changes in these ideas at the time of the study. However, I expected that gender identity would contribute to how fathers viewed themselves, their role and how they managed/coped. Aware of this, I was particularly conscious in developing questions and during interviews to not allow this to influence *how* I

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asked questions. In discussion with my supervisor, I removed the phrase, “as a father…” from questions, as this may have led fathers to over-emphasise their maleness, which may not have been a prominent factor for them. In the analysis, I noticed themes emerging around gender, and initially over-emphasised its importance by making a particular theme ‘coping as a man’, when this was not highlighted by participants. In discussion with my supervisor, she emphasized that I should be developing themes based on what was actually said. I went back to the data again, realized this was not the fathers’ emphasis, and removed ‘as a man’ from the theme title.
Appendix O: Audit trail

The following audit trails present the stages of analysis, for two interview extracts, from initial responses, to superordinate and subordinate themes, to the consequent master-themes and sub-themes for the group.

Example from the theme “Coping responses”

Table 3.

Extract from Paul’s interview

<table>
<thead>
<tr>
<th>Initial responses</th>
<th>Transcript extract</th>
<th>Emergent themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘something happened’-sudden?</td>
<td>Paul: I felt like I was just, something happened and it was almost like being on a rollercoaster. I got a lot of support from the CAMHS team and the GP to start with and then the CAMHS team and then other services. But you just felt like it was just rushing— I felt more like I was being pulled by the process rather than managing, you know, managing the process. It wasn't a process I could manage it was something that I just had to go with and do my best as I went along.</td>
<td>Doing your best whilst being swept along/feeling out of control</td>
</tr>
<tr>
<td>Rollercoaster</td>
<td></td>
<td>------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Services helpful</td>
<td></td>
<td>------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>‘rushing’- being pulled rather than managing</td>
<td></td>
<td>------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Doing his best as went along</td>
<td></td>
<td>------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>

Transformation of the theme over time:

1. Emergent theme: Doing your best whilst being swept along/feeling out of control

2. Subordinate theme: Swept along/automatic response

3. Initial master theme: How fathers care in the context of psychosis

Initial sub-theme: Automatic response

4. Revised master theme: Coping like a man

Final sub-theme: On autopilot
5. Final master theme: Coping responses

Examples from the theme “Men aren’t supposed to talk, but it helps”.

Table 4.

*Extract from Andrew’s interview*

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male code of talking</th>
<th>Football or racing</th>
<th>Code for bonding</th>
<th>Should be hunting</th>
<th>Sport instead</th>
<th>Men talking to each other is hard, but talking to an unrelated woman is okay</th>
<th>You need trust to talk to another man</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Andrew:</strong> Well, women are just unfathomable, but men are weird because we do everything by code. Rather that say it, we kind of find a way of saying it, without saying it. Like talking about football or racing, it’s a complete and utter waste of time, but actually it’s a code for something. It’s a code for social order, for bonding with other people. Because what we’re supposed to be doing is hunting, shooting, and fishing, and fighting each other. What do we do? We invent sport and do it that way. I think the hard thing for men is to talk about it to each other. I mean, you're okay, you're an independent person, so I’ve bared my soul to you. Why I should, I haven't got a clue ‘cos I don’t know you from a hole in the ground, but there you are. If it were another bloke, you would have to feel a great deal of trust in order to do that.</td>
<td>Things men are allowed to talk about to other men</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**2. Initial superordinate theme:** Men and talking

**4. Initial master-theme:** Men and talking: a changing picture

**Initial sub-theme:** There are rules about talking

**5. Final master-theme:** Men and talking: rules and exceptions

**Final sub-theme:** Men aren’t supposed to talk, but it helps

Table 5.

*Extract from John’s interview*

<table>
<thead>
<tr>
<th>Nothing helpful</th>
<th>Interviewer: Is there anything else that-- actually I'm thinking about going to a group or, don't know if you've done something that you felt, &quot;Oh, that was really helpful.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Talking about it won’t change it</td>
<td>John: No. Nothing really. No, nothing. There's nothing out there. There's nothing anyone can do. What you gonna do? Go along and talk about it, have a cup of tea and a slice of cake, isn’t going to change it, is it?</td>
</tr>
<tr>
<td>Hearing other people’s stories not helpful, as everyone different You’ve got to get on with it</td>
<td>Interviewer: No. That's right. Because I was wondering about whether when you hear about other people's experiences, if either you think, oh it's - John: It's not an inspiration or nothing like that. Everyone's different. You've got to get on with it haven't you? It's no comfort, not to me anyway. Going with others saying, oh, my son…. What’s the point?</td>
</tr>
</tbody>
</table>

Talking can’t fix things
And later:

Table 6.

Extract from John’s interview

| Talk to social worker | John: …We used to talk to the social worker and stuff like that. They were always on the phone. They always said, "If you want to know anything, give us a ring" or "If you don’t think something’s, right, give us a ring." We’ve done a lot of that. They didn’t get his tablets right at first and stuff like that. Do this, do that, they’d come around. They’re a fantastic unit. |
| Early intervention rang him | Interviewer: You would get in touch about medication-- |
| Called them a lot | John: Medication, how he was acting, why is he doing this, why is he doing that? Then, they would say why he’s doing it and stuff like that and that would just put your mind at rest. |
| Home visits | Interviewer: Again, I guess that getting information from someone who has it was quite helpful. |
| Fantastic | Interviewee: Yes. Professionals, yes. |
| Medication, behaviour | Helpful to talk to professionals |
| Explanations | |
| Put your mind at rest | |
| Professionals | |

Transformation of the theme over time:

1. Emergent theme: Talking can’t fix things

2. Initial superordinate theme: Men and talking

Initial subordinate theme: Men don’t talk
4. Initial master-theme: Men and talking: a changing picture

Initial sub-theme: Men aren’t supposed to talk

5. Revised master-theme: Men and talking: rules and exceptions

Final sub-theme: Men aren’t supposed to talk, but it helps

Appendix P: Credibility checks

A range of credibility checks were carried out throughout the research process, in order to gain some validation of themes and interpretations of interview data from supervisors and peers. These discussions developed my analysis and enhanced credibility of themes by ensuring interpretations were grounded in participants’ accounts.

Comparing line by line analysis and emergent themes

For the first interview analysed, I initially completed line-by-line analysis to ensure that I was not finding themes based on my own pre-existing hypothesis and assumptions, and limiting confirmation bias (finding what I expected to find). In one peer supervision session, a peer completed line-by-line analysis on the same section of a transcript (see table 7). My peer had interpreted the use of the word ‘laugh’ as evidence of the participant using humour to cope. Whereas I had interpreted the description around the participant’s wife dying as explaining why he might not have noticed his daughter’s psychosis early on, whereas I had interpreted this as the father trying to make sense of why the psychosis had started in the first place. In fact, later in the interview this father suggested that his daughter developing psychosis “might never have happened” if his wife hadn’t died, and it was likely that my knowledge of the rest of the interview was leading me towards this interpretation, although it perhaps was not obvious from this small extract. This exercise taught me to stick closely to what is said in the transcript, as it was possible that this extract held
elements of both interpretations, but to also use my knowledge from the rest of the transcript for areas of ambiguity.

On discussing the interpretation in light of references from later in the interview with my peer, we agreed that my interpretation was likely to be the most accurate representation of the father’s meaning. However, it also brought to light the importance of not holding too strongly to my interpretations and discussing ambiguous sections with another person.

Table 7.

*Line by line analysis by both the researcher and a peer using IPA*

<table>
<thead>
<tr>
<th>Interview extract</th>
<th>Line-by-line analysis (main researcher)</th>
<th>Line-by-line analysis (peer)</th>
</tr>
</thead>
</table>
| P: “My wife, she’d only just passed away in October two years ago so she’s coming up for two years. [daughter] seemed okay for a couple of months, we got to Christmas but then after Christmas I found she suddenly said something to me. We’re going to school in the car and she suddenly said something and I thought, ‘oh, this isn’t right’. My wife had died so I was probably not right. I mean I can’t even evaluate what I felt like at the time. Then two months later, [daughter] suddenly realised, even though she might have been hiding it, because [daughter] wouldn’t necessarily come out straight out, straight away. She might have been hiding things from me for a while. I was” | Wife had just passed away  
Making sense of development of illness?  
Sudden  
‘this isn’t right’  
Confusing time due to circumstances  
Hiding symptoms?  
Tired  
Confusing time | Wife dying as explanation for ‘missing’ symptoms?  
It’s me, not you. ‘I’m not right’  
Dream-like quality?  
Shame in not noticing? |
probably already tired, as I said, I can’t really remember what I was feeling at the time. When I went to CAMHS I said, ‘we both need help’.

<table>
<thead>
<tr>
<th></th>
<th>Asked for help for both of them</th>
<th>Asking for help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question</td>
<td>Answer</td>
<td>Answer</td>
</tr>
</tbody>
</table>


Parental experiences of coping with caring for a son or daughter with psychosis:

An integrative review of the literature

Word count: 7,997
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

Abstract

**Aim:** To investigate the extent to which coping has previously been considered in relation to the stresses/challenges experienced by parents caring for a son or daughter with a diagnosis of psychosis, and to offer a summary and review of this evidence.

**Method:** A review of literature related to coping in parents caring for a son or daughter with psychosis was conducted. Themes were extracted through narrative synthesis and key findings from studies presented for both qualitative and quantitative studies.

**Results:** A number of findings related to how services can support parents. Findings suggest that an engaged, tolerant and loving approach to caring and viewing this as an extension of the parenting role may result in increased caregiver satisfaction. Parents’ acceptance of their child’s illness appears to have a positive impact on both them and their child. Evidence suggests that fathers may approach caring and coping differently to mothers.

**Conclusions:** Professionals can support parents by providing accurate information and encouraging parents to discover what works for their child. Support groups and education courses should be available for parents to take up as needed. By instilling hope and promoting the positive aspects of caregiving for parents, they can be empowered to maintain their caring role. Despite evidence that the experiences and responses of fathers caring for a son or daughter with psychosis may be different to mothers’, there is a lack of focused research around coping in this group.

**Key words:** Adaptation, Psychological; Caregivers; Parents; Psychotic Disorders; Review
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

1. Introduction

In recent years, those with mental health diagnoses have increasingly been cared for by their families (Shah et al., 2010). This has largely been attributed to a shift towards providing community-based care and reducing hospital stays (Magliano et al., 2007). The term ‘family-caregiving’ is used when family members or friends provide unpaid care to chronically ill or functionally impaired persons (Etters et al., 2008; Morris, 2001).

Previous reviews have found carers of those with schizophrenia tended to be wives and sisters (Awad & Voruganti, 2008), or parents, and usually mothers (Baronet, 1999; Bloch et al., 1995; Caqueo-Urízar et al. 2014; Chan, 2011; Jenkins & Schumacher, 1999; Ola, 2013; Wancata et al., 2008). Existing research has focused on female carers and the experiences of men caring for someone experiencing psychosis have not been widely investigated (Sharma et al., 2016; Sin et al., 2005). The little existing research about gender and caring in the context of psychosis suggests that women often spend more time on caregiving than men (Boyer et al., 2012), but that the number of men providing care for a relative with psychosis is increasing (Awad & Voruganti, 2008; Collings, 2009; Ola, 2013). It will therefore be important to capture the experiences of both parents as cultural ideas about the caring role have the potential to create a move towards mothers and fathers co-parenting (Brandth & Kvande, 2018), with fathers already reported to be more involved in caring for their children than in the past (Yeung et al., 2001).

Those caring for someone with psychosis can experience high levels of burden and depression (Papastavrou et al., 2012). Therefore, having effective strategies for managing this role and caring for themselves will enable these carers to
continue to provide support to their family member, whilst minimising the potential negative impacts of the role, e.g. reduced burden (Solomon & Draine, 1995).

When the concept of coping first began to appear in the literature, it was defined as "any response to external life strains that serves to prevent, avoid, or control emotional distress" (Pearlin & Schooler, 1978, p.3). In recent literature, it is more often referred to as the process of responding to stressful events/situations (Folkman et al., 1986). Folkman et al. (1986) viewed this process as remaining somewhat stable across a range of stressful situations. However, evidence suggests that situational factors of a given stressful situation are key in determining coping responses (McCrae, 1984). Various theories around coping have been developed, with the most prominent in mental health literature being Lazarus and Folkman’s transactional theory of stress and coping (1984) and Pearlin’s (1989) stress and coping model. For the purposes of this literature review, coping was defined using Pearlin et al.’s (1990) ‘caregiver stress process model’, adapted from Pearlin’s (1989) stress and coping model. Although similar to Lazarus and Folkman’s transactional model, Pearlin et al. (1990) distinguish between sources of stress in a given situation, with coping influencing each of these stages and not limited to being either emotion- or problem-focused. This model also allows ‘emotion-focused’ coping to be adaptive, rather than being considered a last resort, as in Lazarus and Folkman’s (1984) model (Jansen, 2014).

Pearlin et al.’s (1990) ‘caregiver stress process model’ specifically relates to caregiver stress in the context of Alzheimer’s disease (see figure 1 below). Pearlin et al. (1990) suggest that coping can be understood in terms of: management of the situation resulting in stress; management of the meaning of the situation, thus reducing threat; and management of the stress symptoms resulting from the situation.
In this way, coping is thought to explain the association between the stressor and observed strains/ outcomes, thus acting as a mediator.

Figure 1. Simplified version of Pearlin et al. (1990)’s stress process model conceptualising Alzheimer’s caregivers’ stress

Pearlin et al. (Pearlin et al., 1990; Pearlin & Aneshensel, 1986; Pearlin & Schooler, 1978) suggest that the efficacy of coping can be evaluated only through the analysis of its mediating effects at various junctures of the stress process. Although not included in the model shown here, coping is also thought to moderate the effect of a stressor on strains/ outcomes for an individual, being described as a ‘stress buffer’ (Pudrovska et al., 2005).

Existing research in the area of parents caring for children experiencing psychosis was reviewed in 2017 by Klages et al., which concluded that coping was an important area for future consideration, as informal caregivers are ‘an invaluable resource’ (Klages et al. 2017).
The aims of this literature review were to:

Identify, review, critically appraise and synthesise primary empirical papers reporting on coping or related constructs (e.g. managing or responding) in parents caring for a son/daughter with psychosis.

Present evidence of ways of coping which appeared to be helpful or have a positive impact on the situation itself, the way that the parents understood the situation, or the stress experienced by the parent, as per Pearlin et al.’s (1990) model.

2. Method

2.1 Eligibility criteria

Studies which measured or reported on ‘coping’ or related constructs (e.g. adapting) and the focus of which was parents providing care to their child experiencing psychosis were eligible for inclusion in the current literature review. Studies were required to be peer-reviewed primary empirical papers, with no limitation on methodological design. Studies had to include a careReceiver formally diagnosed with psychosis. Publication date was limited by those available within the search engines used (see ‘search strategy’ for dates). No limitation on country of publication was employed, however only English-language articles were included due to limitations in time and resources in the current review.

2.2 Search strategy

Searches of the electronic databases PsycINFO, Psychology and Behavioral Sciences Collection, PsycARTICLES, CINAHL, MEDLINE and the Web of Science Core Collection: Citation Indexes were conducted on 9th June 2017 for studies undertaken with date of publication being limited by the restrictions of particular search engines (PsycINFO: 1800s - present, Psychology and Behavioral Sciences Collection: 1965 - present, PsycARTICLES: 1894 - present, CINAHL: 1981 -
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

present, MEDLINE: 1966 - present, and the Web of Science Core Collection: Citation Indexes: 1900 - present). In addition, hand searching of relevant articles was conducted to identify additional potentially relevant articles. These articles all underwent initial screening by title, then by abstract, followed by full-text review where eligible.

Search terms were developed from a preliminary search of existing studies in the area of coping in parent caregivers of people with psychosis. Search terms included a combination of thesaurus terms for the four concept areas of ‘parents’, ‘carers’, ‘coping’, and ‘psychosis’, and a Boolean search strategy was employed. The first search string was used for the databases PsycINFO, Psychology and Behavioral Sciences Collection, PsycARTICLES, CINAHL, MEDLINE (via EBSCOhost); TI (father* OR dad* OR paternal OR mother* OR mom* OR mum* or maternal* or parent*) AND TI (psychosis OR psychoses or schizophreni* or psychotic) AND SUB (adapt* OR coping OR strategies OR skills OR cope* OR mechanisms OR resilien* OR post-traumatic growth OR experience*).

For searching in the Web of Science Core Collection, the same search terms were used, but the category ‘TOPIC’ replaced ‘SUBJECT’.

2.3 Study selection

This search yielded 453 results, with 8 identified through others sources. 84 duplicates were removed, leaving 377 studies. The 377 papers were then screened initially by title against the inclusion criteria, with ambiguous titles being passed onto the next stage of screening. A total of 115 papers were then screened by abstract against the inclusion criteria. 38 papers underwent full-text scrutiny.
2.4 Inclusion/exclusion criteria

Studies were excluded where coping was not measured or reported in the results section, leaving 25 papers. See figure 2 below for PRISMA (2009) flow diagram of search strategy.
Records identified through database searching (n = 453)

Records after duplicates removed (n = 377)

Records screened by title (n = 377)

Records excluded (n = 262)

Records screened by abstract (n = 115)

Records excluded (n = 77)

Full-text articles assessed for eligibility (n = 38)

Records excluded: Not enough evidence of coping concepts (n = 6)
Burden only (n = 2)
Non-empirical paper (n = 2)
Failed quality screening (n = 3)

Studies included in narrative synthesis (n = 25)

Figure 2. PRISMA (2009) flow diagram of literature search (Moher et al., 2009)
2.5 Assessment of study quality

For assessing the quality of the nineteen qualitative studies, three tools were considered: an iterative guide to quality assessment, developed by Mays and Pope (2000), a qualitative assessment framework developed by Spencer et al. (2003) and adapted by MacEachen et al. (2006), and the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies (CASP, 2013). The CASP was selected, having clear, focused questions to guide the quality assessor and considering all of the key considerations from Mays and Pope, but with additional consideration of some items (e.g. sources of researcher bias). In the current review, additional prompts were added to the CASP, drawn from guidelines by Elliott et al. (1999) and Yardley (2000), as well as an additional question regarding relevant theory/literature.

Five of the six quantitative studies were of a quantitative descriptive design, with one being a cross-sectional analytic study (St-Hilaire et al., 2007). Three tools were identified to assess their quality: Critical Appraisal of a Cross-Sectional Study (Survey) (Center for Evidence Based Management, 2014), ‘11 questions to help you make sense of descriptive/cross-sectional studies’ (Albert Einstein College of Medicine, 2002), and ‘Questions to assist with the critical appraisal of a cross-sectional study (Type IV evidence)’, an adapted version of the CASP (Public Health Wales Observatory, 2014). As these tools contained similar questions, an adapted version of the CASP for case control studies (CASP, 2010) was selected to assess quantitative study quality. Additional prompts were informed by the Strobe statement, and recommendations from Sanderson et al. (2007) and Guyatt et al. (1993).

The two studies of mixed methodology were assessed using the Mixed Methods Appraisal Tool (Pace et al., 2012; Pluye et al. 2009). The MMAT is the
only tool known to be developed for appraising mixed method studies. The emphasis of the CASP and MMAT is on methodological criteria rather than reporting quality, which may be misleading (Huwiler-Müntener et al., 2002; Mhaskar et al., 2012).

Both the MMAT and the CASP have been used in systematic reviews in the area of adult mental health, including first-episode psychosis (Gronholm et al., 2017; Sin & Norman, 2013). The assessment of quality was largely for the purpose of assessing the contribution of each paper, as discussed in other reviews (e.g. Malpass et al., 2008), rather than assigning a numerical quality ‘score’ to studies. Milliken (2001), Ferriter and Huband (2003) and Hanzawa et al. (2008) were excluded during quality screening, as they did not state clear research aims. Ferriter and Huband (2003), and Hanzawa et al. (2008) also failed to identify their studies as mixed methods and only presented a qualitative or quantitative research aim respectively. No study was excluded based on quality. A final total of nineteen qualitative and six quantitative studies are reviewed in this paper.
Table 1.
Quality Assessment of Qualitative Studies (Adapted CASP Checklist for Qualitative Studies (CASP, 2013)).

<table>
<thead>
<tr>
<th>Screening questions</th>
<th>Quality assessment questions</th>
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<tbody>
<tr>
<td>1) Clear statement of aims?</td>
<td>1) Qualitative methodology appropriate?</td>
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<td>2) Qualitative methodology appropriate?</td>
<td>3) Research design appropriate?</td>
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<td>6) Relationship between researcher and participants adequately considered?</td>
<td>7) Ethical issues considered?</td>
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<td>7) Ethical issues considered?</td>
<td>8) Data analysis sufficiently rigorous?</td>
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<td>8) Data analysis sufficiently rigorous?</td>
<td>9) Clear statement of findings?</td>
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<td>9) Clear statement of findings?</td>
<td>10) How valuable is the research?</td>
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<td>10) How valuable is the research?</td>
<td>11) Appropriate theory/literature considered?</td>
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<td>11) Appropriate theory/literature considered?</td>
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<td>Knudson &amp; Coyle, 2002</td>
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<td>Nyström &amp; Svensson, 2004</td>
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<td>Osborne &amp; Coyle, 2002</td>
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<td>Pejlert, 2001</td>
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<td>Rudge &amp; Morse, 2004</td>
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<td>Rungreangkulkij &amp; Chesla, 2001</td>
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<td>Wintersteen &amp; Rasmussen, 1997</td>
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1 = yes, 0 = no, ? = can’t tell
Table 2.
**Quality Assessment of Quantitative Studies (Adapted CASP Checklist for Case-Control Studies (CASP, 2010))**

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<td>Ghosh &amp; Greenberg, 2012</td>
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1 = yes, 0 = no, ? = can’t tell
## FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

### Table 3.

**Reliability/Validity Information for Measures in Quantitative Studies**

<table>
<thead>
<tr>
<th>Study</th>
<th>Measures used</th>
<th>(C) Cronbach alpha measure of internal consistency or reliability measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ghosh &amp; Greenberg, 2012</td>
<td>Zarit Burden Interview (Zarit, Reever, &amp; Bach-Peterson, 1980)</td>
<td>(C) .86 (fathers &amp; mothers)</td>
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<tr>
<td></td>
<td>Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977)</td>
<td>(C) .90 (fathers) &amp; .88 (mothers)</td>
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<td></td>
<td>Multidimensional Psychological Well-Being Scale (Ryff, 1989)</td>
<td>(C) .80 (fathers) &amp; .79 (mothers)</td>
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<td></td>
<td>Instrumental Activities of Daily Living Index (Seltzer &amp; Krauss, 1989)</td>
<td>(C) .79 (fathers) &amp; .77 (mothers)</td>
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<td></td>
<td>Schizophrenia Outcome Module (Cuffel, Fischer, Owen, &amp; Smith, 1997)</td>
<td>(C) .80 (fathers) &amp; .89 (mothers)</td>
</tr>
<tr>
<td></td>
<td>Marital Satisfaction Questionnaire for older adults (Haynes et al., 1992)</td>
<td>(C) .80 (fathers) &amp; .89 (mothers)</td>
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<td></td>
<td>Modified version of the Social Participation Scale (scores from 0-32; Sweet &amp; Bumpass, 1987)</td>
<td>(C) .95 (fathers) &amp; .94 (mothers)</td>
</tr>
<tr>
<td>Greenberg et al., 2004</td>
<td>Personal Growth, Self-Acceptance, and Purpose In Life subscales from Ryff’s (1989) measure of psychological well-being</td>
<td>N/A</td>
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<tr>
<td></td>
<td>CES-D Scale</td>
<td>(C) .86</td>
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<td>Positive Affect Scale (quality of relationship; Bengtson &amp; Schrader, 1982)</td>
<td>(C) .89</td>
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<td></td>
<td>Life Orientation Test (dispositional optimism; Scheier &amp; Carver, 1985)</td>
<td>(C) .90</td>
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<tr>
<td></td>
<td>Inventory for Client and Agency Planning (count of number of current behavioural problems in adult child in each domain; Bruininks, Hill, Weatherman, &amp; Woodcock, 1986)</td>
<td>(C) .81</td>
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<tr>
<td>Hall &amp; Docherty, 2000</td>
<td>Scale for Assessment of Positive Symptoms (SAPS; Andreasen, 1982)</td>
<td>N/A</td>
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<tr>
<td></td>
<td>Camberwell Family Interview (CFI; Brown &amp; Rutter, 1966; Vaughn &amp; Leff, 1976)</td>
<td>Interclass correlation coefficient of .84</td>
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<td></td>
<td>Assertive Coping Scale of Strategic Approach to Coping Scale (SACS; Hobfoll et al., 1993), some items removed to improve Cronbach alpha</td>
<td>Intraclass reliability ratings with an associated research group of r &gt; .80 for criticism and r &gt; .75 for Emotional Over Involvement (EOI).</td>
</tr>
<tr>
<td>Hobbs, 1997</td>
<td>Measure of burden: Noh &amp; Turner’s (1987) 9-item modified version of Pasamanick et al.’s (1967) “Patient Behavior Scale”</td>
<td>(C) .64†</td>
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<tr>
<td></td>
<td>Economic stress: Ross &amp; Huber’s (1985) 3-item modified version of</td>
<td>(C) .97</td>
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PEARLIN et al.’s (1981) Economic Strain Scale  
Physical health: Wahler Physical Symptoms Inventory (Wahler, 1983)  
Discrete Life Events: 25-item modified version of the Louisville Older Persons Events Scale (Murrell et al., 1981).  
Coping: Pearlin & Schooler’s (1978) Mastery Scale  
Social support: Pearlin et al.’s (1990) Expressive Support Scale  
Depression: CED-S  

Morin & St-Onge, 2015  
Experience of Caregiving Inventory (Szmukler et al., 1996)  
The Well-Being Scale (Tebb, 1995)  
The Family Empowerment Scale (Koren et al., 1992)  
The Family/Professional Collaboration Scale (DeChillo et al., 1994)  

St-Hilaire et al., 2007  
Strategic Approach to Coping Scale (SACS; Hobfoll et al., 1993)  
Clinical psychologist diagnosed schizophrenia  

Family history of psychosis was determined by number of relatives diagnosed with schizophrenia, with Low Family Exposure (LFE) being assigned to parents with only one relative with the diagnosis, and High Family Exposure (HFE) being assigned to parents with at least one other relative with a ‘suspected’, ‘probable’ or ‘definite’ designation of a psychotic disorder.

†Questionable internal consistency, ‡poor internal consistency (George & Mallery, 2003)
3. Results

3.1 Strengths and limitations of qualitative studies

All of the nineteen qualitative studies had a clear rationale for their research and chose an appropriate design and analysis for their question.

Nine studies (Blomgren Mannerheim et al., 2016; Chesla, 1991; Howard, 1994; Jung, 2000; Knudson & Coyle, 2002; Nyström & Svensson, 2004; Osborne & Coyle, 2002; Pejlert, 2001; Rudge & Morse, 2004) provided some reflection of their own perspective in relation to existing theory and their own values, a central criterion within the qualitative research tradition (Elliott et al., 1999).

All but two (Chen et al., 2016; Wintersteen & Rasmussen, 1997) of the nineteen qualitative studies gave clear and convincing examples of themes using extracts from interviews.

 Whilst all but two (Jung, 2000; Landon et al., 2016) of the studies discussed gaining participant consent, only four discussed participant drop-outs or non-participation, with Chesla (1991), Landon et al. (2016), and Pejlert (2001) providing reasons for non-participation.

Five studies (Blomgren Mannerheim et al., 2016; Landon et al., 2016; Nyström & Svensson, 2004; Rudge & Morse, 2004; Wintersteen & Rasmussen, 1997) failed to mention bias in sampling due to membership of a support group or ‘National Fellowship’. Results were clearly reported in most (16/19) studies, with Howard (1994) and Poonnotok et al. (2016) presenting an integrated summary using a figure with boxes and arrows, which is considered ‘good practice’ in qualitative research studies (Elliott et al., 1999). Pejlert (2001) also presented themes in table form. Conversely, Wintersteen and Rasmussen (1997) presented a large number of results that lacked clarity when presented.
In conclusion, findings from Chen et al. (2016), Chesla (1991), and Winstersteen and Rasmussen (1997) are presented with some caution and those from Rungreangkulkij and Chesla (2001) with additional caution, having successfully answered fewer than half of the questions in the quality assessment tool.

3.2 Strengths and limitations of quantitative studies

All six of the quantitative research papers presented clear rationales for their research, with an appropriate design for their investigation.

First, the extent to which studies have used appropriate, reliable and valid measures will be discussed. The degree to which a tool reliably measures what it intends to measure is essential for assessing whether the findings can be ‘trusted’ and the extent of their usefulness or contribution to the research area.

Appropriate sampling was used and reasons for non-participation were given in all studies except Greenberg et al. (2004), where the sample was drawn from a previous study (not referenced) and the recruitment process is not fully described.

Morin and St-Onge (2015) were the only authors to report on the demographics of those who declined participation. None of the included papers describe how the sample size was arrived at, and no power calculations are given.

Analyses for all quantitative studies were appropriate for their research questions. However, Hall and Docherty (2000) conducted many analyses with a relatively small number of participants (n = 44), which reduces the study’s power to detect a significant effect. For Ghosh and Greenberg (2012), Hobbs (1997), and Morin and St-Onge (2015), $R^2$ values and p-values for their multiple regression analyses were provided. However, as there was no discussion of residual plots to determine whether the models were a good ‘fit’ for the data, these values may be misleading.
Confounders were identified and accounted for in calculations for all studies, but Hall and Docherty (2000) failed to mention factors such as whether the child lived at home in their analyses of gender differences.

Data were collected for all studies using self-report measures, with the addition of interviews in Ghosh and Greenberg’s (2012) and Hall and Docherty’s (2000) studies. Although self-report measures can be unreliable, there are few alternatives to acquiring the type of information obtained and their use across all studies makes results comparable. St-Hilaire et al.’s (2007) was the only study to include controls in their analyses.

In conclusion, findings from the majority of the included quantitative studies are considered to be reliable. However, those of Hall and Docherty (2000) are presented with some caution due to the large number of analyses conducted and the questionable reliability of the Assertive Coping Scale (Cronbach’s alpha of .64), especially as a more reliable measure of coping (the Strategic Approach to Coping Scale or SACS) was available at the time of publication. The only confounding factor accounted for in their analyses was gender. Hobbs’ (1997) findings relating to life events should also be viewed with caution, as this measure achieved a Kuder-Richardson reliability coefficient of .58. Although comparable to other measures of life events, this demonstrates poor reliability (George & Mallery, 2003).

3.3 General summary of papers surveyed and study characteristics

Although the search criteria was intentionally non-diagnosis specific (simply looking for references to ‘psychosis’ or ‘schizophrenia’), all of the included articles investigated parents caring for a son or daughter with a diagnosis of schizophrenia, with Ghosh and Greenberg (2012) including a diagnosis of schizoaffective disorder. See tables 4 and 5 respectively for characteristics of included qualitative and
quantitative studies. Characteristics of Rudge and Morse (2004) are not shown, as themes are not presented here (see results).
### Table 4.
Characteristics of Qualitative Studies Included in the Literature Review (n=19)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Aims</th>
<th>Sample/Setting</th>
<th>Design/Analysis</th>
<th>Main findings</th>
<th>Coping lit?</th>
<th>Coping theory?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blomgren Mannerheim et al. (2016)</td>
<td>To systematically describe and analyse the meaning of parents’ care responsibility for their adult child with a diagnosis of schizophrenia.</td>
<td>5 mothers and 3 fathers (age 52-63) with ≥5 years’ experience caring for their adult child diagnosed with schizophrenia. Members of an interest association for schizophrenia in Sweden.</td>
<td>Interviews. Analysed using hermeneutic deductive &amp; inductive method of interpretation.</td>
<td>Parents organised their world in the form of strategy projects, which produced stability in their child and enabled them to relax more. Benefits from successful ‘work projects’ and ‘recreation projects’.</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Chen et al. (2016)</td>
<td>To develop a pathway model of parental help seeking for adolescents experiencing a first episode of psychosis (FEP) and identify crucial time points for intervention.</td>
<td>13 mothers and 3 fathers residing or in regular contact with their 13-17yr-old child, diagnosed with a schizophrenia spectrum disorder in New York (USA).</td>
<td>Interviews. Analysed using content analysis.</td>
<td>Proposed a parental help seeking for FEP model, with ‘considering options’ as part of the first ‘contemplation stage’. The ‘action stage’ entailed ‘help-seeking intention’, ‘securing help’ and ‘service appraisal’.</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Chesla (1991)</td>
<td>To provide an interpretative account of parents caring practices that evolved in response to the demands of living with a son or daughter diagnosed with schizophrenia.</td>
<td>13 mothers and 8 fathers (age 50-77) from 14 families who cared for a son or daughter diagnosed with schizophrenia and were members of community family support groups in the USA.</td>
<td>Naturalistic study. Observations and Berkeley stress and coping interpretive interview. Analysed using hermeneutic interpretation.</td>
<td>Distinct caring practices identified: ‘Engaged care’ parents appeared the most satisfied. ‘Managed care’ parents experienced the caring role as a full-time job. ‘Distanced care’ fathers appeared relatively unburdened, but missed out on daily progress in their son/daughter.</td>
<td>Y</td>
<td>N</td>
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<tr>
<td>Donnelly (2005)</td>
<td>To explore mental health</td>
<td>7 mothers and 3 fathers</td>
<td>Interviews and field notes.</td>
<td>When traditional healing</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td><strong>Howard (1994)</strong></td>
<td>To describe caregiving experiences of mothers from onset of the children’s mental illness to the present; and to examine the problems and processes of their caregiving role.</td>
<td>10 white mothers (age 49-85) of children aged 18+ diagnosed with schizophrenia. From middle-income or affluent areas of South-East USA. Members of a State Alliance for the Mentally Ill.</td>
<td>Interviews using naturalistic inquiry. Analysed using grounded theory.</td>
<td>Understanding their child’s diagnosis resulted in parents providing more support to one another. Fathers learned specific responses to situations from various informational sources. Hope was a ‘sustaining factor’ for mothers.</td>
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<tr>
<td><strong>Howard (1998)</strong></td>
<td>To describe the lived experience of fathers of adult children with schizophrenia by exploring the extent to which they engaged in caregiving.</td>
<td>12 fathers (age 49-76) with an adult child diagnosed with schizophrenia in the USA. Fathers had provided care for their child an average of 15.7 years.</td>
<td>Interviews using theme extrapolation and theme refinement tools using naturalistic inquiry, over a 2-year period. Analysed using constant-comparative method.</td>
<td>Various ways of learning and coping identified, including acceptance and facilitators to acceptance. Acceptance of the illness was indicated in all fathers who completed the theme refinement tool (n = 11).</td>
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</tr>
<tr>
<td><strong>Jung (2000)</strong></td>
<td>To understand the experiences of Korean mothers who are taking care of their children with a diagnosis of schizophrenia.</td>
<td>2 Korean mothers (aged 42 and 52) of children diagnosed with schizophrenia.</td>
<td>Interviews. Analysed using Heiddegerian hermeneutic phenomenology.</td>
<td>One mother was able to engage in ‘intense nurturing’ of her child and...</td>
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**FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS**

beliefs and help seeking attitudes from the family caregiving perspective of 10 Korean American parents of children with a diagnosis of Schizophrenia. (age 38-76), immigrant Korean Americans and caregivers of adult children with a diagnosis of Schizophrenia in the USA. All members of a family support group in an Asian Mental Health Clinic (urban community).

Interviews in participants' native Korean language. Analysed using an interpretive-hermeneutic phenomenological approach.

methods didn't stabilize their children's psychotic symptoms, parents sought Western treatment and learned Western interpretations of symptoms. In the theme 'dancing with the rhythms of symptoms', the mood of the family home was dependent on the child’s symptoms...
<table>
<thead>
<tr>
<th>Researchers</th>
<th>Design</th>
<th>Participants</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knudson &amp; Coyle (2002)</td>
<td>Used a coping framework (Lazarus &amp; Folkman, 1984) to explore experiences of caring for a son or daughter with schizophrenia.</td>
<td>6 mothers and 2 fathers (age 54-73) of people diagnosed with schizophrenia. All British, white and married. Recruited from carer support groups (National Schizophrenia Fellowship) in South-East of England, UK.</td>
<td>Interviews. Analysed using thematic analysis.</td>
<td>Available resources: social support, self-help groups, mental health services. Coping strategies shifted from problem-focused to more emotion-focused forms (e.g. acceptance).</td>
</tr>
<tr>
<td>Landon et al. (2016)</td>
<td>An explorative qualitative study of parents providing long-term care for an adult child with schizophrenia in the New Zealand context.</td>
<td>5 mothers and 1 father (age 58-73), primary caregivers for their son with a diagnosis of Schizophrenia in New Zealand.</td>
<td>Semi-structured interviews. Analysed using a thematic analysis.</td>
<td>Information important for parents in coping with experiences. Research helped them understand their son’s symptoms and feel more empathy. Half the participants no longer attended support groups regularly, as coping better.</td>
</tr>
<tr>
<td>McAuliffe et al. (2014)</td>
<td>To explore the meaning of caregiving for Irish families.</td>
<td>5 mothers and 1 father (age 60-77) of an adult child diagnosed with schizophrenia in Ireland. Parents had cared for their child in their own homes for at least 2 years.</td>
<td>Semi-structured interviews. Analysed using an eclectic approach described by Creswell (2002).</td>
<td>In the theme ‘coping with enduring illness’, adopting a positive stance was considered ‘essential in coping’.</td>
</tr>
<tr>
<td>Nyström</td>
<td>Research question: how</td>
<td>7 fathers (age 63-78),</td>
<td>Interviews.</td>
<td>Themes: ‘Putting up with’</td>
</tr>
</tbody>
</table>
### FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Research Question</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Svensson (2004)</td>
<td>Does a severely mentally ill adult child affect his or her father’s life situation in short- and long-terms?</td>
<td>whose children were diagnosed with schizophrenia more than 20 years ago in Sweden. At the time of interview, the “children” were middle-aged. Analysed using a life-world hermeneutic approach.</td>
<td>humiliation in order to get help’ and ‘Finding an important role as provider of practical support’. Meeting people in similar situations and being able to ‘escape’ from time to time was helpful.</td>
</tr>
<tr>
<td>Osborne &amp; Coyle (2002)</td>
<td>To explore parental responses to having a child diagnosed with schizophrenia, with the research being informed by existing models of grief.</td>
<td>3 mothers and 1 father of adult children diagnosed with schizophrenia in Surrey, UK. Recruited through the National Schizophrenia Fellowship in Surrey. Interviews. Analysed using Interpretative Phenomenological Analysis</td>
<td>One mother described her husband as having ‘distanced himself psychologically’, concentrating on work. Support from others and having her ‘own life as well’ helped. The one father used acceptance and distancing himself from the illness both mentally and physically.</td>
</tr>
<tr>
<td>Pejlert (2001)</td>
<td>To illuminate the meaning of parental caregiving with reference to having an adults son or daughter with severe mental illness in a care setting.</td>
<td>3 couples, 1 father, and 1 mother of adult children who had lived in a community supported housing project in Sweden for 2 years and had a diagnosis of schizophrenia. Narrative interviews. Analysed using a phenomenological hermeneutic approach.</td>
<td>Acceptance of the illness and support from others were found to be helpful. Hope was found to be a ‘sustaining force’.</td>
</tr>
<tr>
<td>Study</td>
<td>Objectives</td>
<td>Participants</td>
<td>Methods/Analytical Framework</td>
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</tr>
<tr>
<td>Poonnotok (2016)</td>
<td>To explore parental caregiving processes in Thailand during the early phase of schizophrenia.</td>
<td>17 mother and 8 fathers (age 44-77), Thai parents of adult children diagnosed with schizophrenia within the last five years in Thailand.</td>
<td>Interviews using a Straussian grounded theory approach. Analysed using constant comparative analysis.</td>
</tr>
<tr>
<td>Rungreangkulij &amp; Chesla (2001)</td>
<td>To investigate how beliefs about mental illness are expressed in Thai families, what the family help-seeking patterns are in the presence of schizophrenia, and how Thai mothers respond to having an adult child diagnosed with schizophrenia at home.</td>
<td>12 Thai mothers (age 40-64) of adult children with a diagnosis of schizophrenia in Thailand. Most were farmers, married and educated at an elementary school level.</td>
<td>Interviews. Analysed using Interpretive phenomenology.</td>
</tr>
<tr>
<td>Ryan (1993)</td>
<td>To gain an understanding of the experience of mothers living with an adult child with schizophrenia.</td>
<td>5 mothers (age 50-62) of an adult child with a diagnosis of schizophrenia in Canada. All employed, married, Caucasian women. Recruited from a support group.</td>
<td>Interviews. Analysed using a descriptive qualitative design using the ethnographic method</td>
</tr>
<tr>
<td>Skubby et al. (2015)</td>
<td>To understand the experiences of parents as they sought psychological and specialized medical services for a loved one</td>
<td>8 mothers and 3 fathers (7 white and 4 black). 3 couples and 5 individuals. Parents of adult children with a diagnosis of schizophrenia in Canada.</td>
<td>Interviews. Analysed using an issue-focused analysis.</td>
</tr>
<tr>
<td>Wintersteen &amp; Rasmussen (1997)</td>
<td>To explore reactions when fathers come face to face with the mental illness of an adult child.</td>
<td>Having a first episode of psychosis.</td>
<td>Recruited from child and family services agency in Ohio, USA. 25 mothers (age 46-77) and 25 fathers (age 48-79) of a son or daughter with a diagnosis of schizophrenia in a midwestern state in USA. Recruited from support groups (68%) or regional treatment centre (32%).</td>
</tr>
</tbody>
</table>
### Table 5.
*Characteristics of Quantitative Studies Included in the Literature Review (n=6)*

<table>
<thead>
<tr>
<th>Authors</th>
<th>Aims</th>
<th>Sample/Setting</th>
<th>Design/Analysis (see Table 3 for measures used and reliability)</th>
<th>Main findings</th>
<th>Coping lit?</th>
<th>Coping theory?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ghosh &amp; Greenberg (2012)</td>
<td>To explore the extent to which marital satisfaction and social participation buffer the negative effects of caregiving stress on adaptation for fathers and mothers. To assess whether caregivers value social participation or marital satisfaction more.</td>
<td>100 caregiving couples with a son or daughter with schizophrenia or schizoaffective disorder in Wisconsin, USA. Fathers (aged 71.1 ± 8.7), mothers (aged 68.6 ± 7.8).</td>
<td>Quantitative descriptive study. Repeated measures ANCOVA to assess differences within married couples. Regression for predictors of burden, depression, and psychological well-being. Separate regression models were run for fathers and mothers to test buffering effect of coping resources on caregiving stressors.</td>
<td>Social participation significantly predicted fewer depressive symptoms and improved psychological wellbeing for both mothers and fathers. Fewer depressive symptoms were predicted only for fathers providing greater levels of assistance. Social participation significantly predicted lower subjective burden in fathers only. Mothers who provided a lot of assistance experienced greater positive well-being by engaging in fewer social activities.</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Greenberg et al. (2004)</td>
<td>To test the hypotheses that the quality of the mother’s relationship with her adult child will be positively related to wellbeing, higher levels of optimism will be related to better maternal wellbeing, and level of Optimism fully mediated effect of quality of relationship on depression (and partly well-being) for mothers.</td>
<td>292 mothers (mean age = 69.3) of adults with Schizophrenia diagnosis (74% son) in USA. All were married. The majority recruited through the state or county agencies responsible for</td>
<td>Quantitative descriptive study. Hierarchical regression analyses to test effect of mother-child relationship on wellbeing and effect of Optimism on maternal well-being.</td>
<td>Optimism fully mediated effect of quality of relationship on depression (and partly well-being) for mothers.</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>
optimism will mediate the effect of the quality of the mother/adult child relationship on maternal well-being.

Moderator-mediator variable distinction (Baron & Kenny, 1986) to test whether optimism mediated the effect of mother-child relationship on maternal well-being.

### Hall & Docherty (2000)

To test the hypotheses that parents high in criticism would report using less assertive and more aggressive coping strategies than those low in criticism, parents high in Emotional Over Involvement (EOI) would report more assertive and aggressive, and less avoidant coping styles than those low in EOI, and both criticism and EOI would be associated with less use of social coping strategies, specifically social support seeking and social joining. 44 parents (mean age 60.5 ± 9.6) of 24 adult outpatients diagnosed with schizophrenia. 19 parent pairs and 6 unpaired parents in Ohio (USA). All patients were in outpatient treatment and receiving antipsychotic medication.

Parents with more assertive coping styles were less critical of their child. Parents who were assertive and had nonaggressive children made fewer critical comments than assertive parents with aggressive children.

### Hobbs (1997)

To test the hypotheses that stressors will exhibit direct, positive effects on depression, stressors will exhibit direct, negative effects on mediators (coping and social support), and stressors will exhibit indirect, positive effects (via mediators) on 100 mothers of adult sons with schizophrenia. They were black, elderly, low-income, unmarried from Birmingham, Alabama. Clients had DSM III-R diagnosis of schizophrenia and were living with mother.

Coping (as mastery) reduced depression, and physical health problems increased depression by the largest amount. Social support reduced depression, but the effect was less than half that of coping on depression. Coping mediated the

<table>
<thead>
<tr>
<th>Hall &amp; Docherty (2000)</th>
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<tbody>
<tr>
<td>To test the hypotheses that parents high in criticism would report using less assertive and more aggressive coping strategies than those low in criticism, parents high in Emotional Over Involvement (EOI) would report more assertive and aggressive, and less avoidant coping styles than those low in EOI, and both criticism and EOI would be associated with less use of social coping strategies, specifically social support seeking and social joining. 44 parents (mean age 60.5 ± 9.6) of 24 adult outpatients diagnosed with schizophrenia. 19 parent pairs and 6 unpaired parents in Ohio (USA). All patients were in outpatient treatment and receiving antipsychotic medication.</td>
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<table>
<thead>
<tr>
<th>Hobbs (1997)</th>
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<tbody>
<tr>
<td>To test the hypotheses that stressors will exhibit direct, positive effects on depression, stressors will exhibit direct, negative effects on mediators (coping and social support), and stressors will exhibit indirect, positive effects (via mediators) on 100 mothers of adult sons with schizophrenia. They were black, elderly, low-income, unmarried from Birmingham, Alabama. Clients had DSM III-R diagnosis of schizophrenia and were living with mother.</td>
</tr>
<tr>
<td>Study</td>
</tr>
<tr>
<td>-------</td>
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<tr>
<td>Morin &amp; St-Onge (2015)</td>
</tr>
<tr>
<td>St-Hilaire et al. (2007)</td>
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</table>
FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS

Of the twenty-five included studies, twelve explicitly set out to investigate coping, either by using a coping framework (Knudson & Coyle, 2002; St-Hilaire et al., 2007), asking questions related to coping (Landon et al., 2016; Osborne & Coyle, 2002), measuring coping or an aspect of coping using a questionnaire (Ghosh & Greenberg, 2012; Greenberg et al., 2004; Hall & Docherty, 2000; Hobbs, 1997; St-Hilaire et al., 2007), or simply exploring how parents respond (Wintersteen & Rasmussen, 1997) or adapt (Morin & St-Onge, 2015) or seek help (Chen et al., 2016; Rungreangkulkij & Chesla, 2001). The remaining nine studies sought to investigate some aspect of the caring experience/practice.

Themes were extracted through narrative synthesis (Popay et al., 2006), with the first author identifying concepts related to coping in included studies (e.g. ‘acceptance’ or ‘support groups’). Through discussion with two supervisors, ambiguous themes were identified as either having enough evidence to support a theme or not, with poorly-represented themes not included. Key findings from studies are presented by theme for all studies (table 6).
Table 6.

Themes Identified from Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Coping with the situation</th>
<th>View caring as management/practical support</th>
<th>Finding new meaning in the caring role</th>
<th>Acceptance</th>
<th>Positive attitude/hope</th>
<th>Optimism, empowerment and mastery</th>
<th>Coping with stress from situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blomgren, Mannerheim et al., 2016</td>
<td>Gathering information for how to manage the situation</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>Self-help groups</td>
</tr>
<tr>
<td>Chen et al., 1991</td>
<td>Engaged versus distanced care</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
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<tr>
<td>Chen, 2005</td>
<td>Help-seeking</td>
<td>x</td>
<td>x</td>
<td>x</td>
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<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Ghosh &amp; Greenberg, 2012</td>
<td>Prosocial and antisocial coping strategies</td>
<td>x</td>
<td>x</td>
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<td>x</td>
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<td>x</td>
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<td>Greengberg et al., 2004</td>
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<tr>
<td>Hall &amp; Docherty, 2000</td>
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<td>Hobbs, 1997</td>
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<td>Howard, 1994</td>
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<td>Howard, 1998</td>
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<td>Jung, 2000</td>
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<td>Knudson &amp; Coyle, 2002</td>
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<td>Landon et al., 2016</td>
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<td>McAuliffe et al., 2014</td>
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<tr>
<td>Morin &amp; St-Onge, 2015</td>
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<td>Nystrom &amp; Svensson, 2004</td>
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<td>Osborne &amp; Coyle, 2002</td>
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<td>Peijert, 2001</td>
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<td>Poonnotok et al., 2016</td>
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<tr>
<td>Rungreangkulkij &amp; Chesla, 2001</td>
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<td>Ryan, 1993</td>
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<tr>
<td>Skubbey et al., 2015</td>
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<td>St-Hilaire et al., 2007</td>
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<tr>
<td>Wintersteen &amp; Rasmussen, 1997</td>
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</table>

FATHERS CARING AND COPING IN THE CONTEXT OF PSYCHOSIS
3.2 Results related to coping from qualitative studies

A narrative synthesis of the themes extracted from the primary studies is presented here. Where concepts were identified in more than one study, these were discussed with two supervisors to confirm their presence across studies. Theme titles were generated through discussion with the two supervisors and were chosen to capture the essence of the concept running through original papers. Where an appropriate title was used in a paper, this was adopted as the title for the theme across papers. Findings which were only present in a small number of studies (i.e. 1 or 2) are not discussed here. Therefore, findings from Rudge and Morse (2004) are not discussed.

Identified themes appeared to fit well within Pearlin et al.’s (1990) caregiver stress process model. This model was therefore used as a framework for presenting results to aid understanding. Findings from qualitative studies are explored first.

3.2.1 Coping with the situation

3.2.1.1 Gathering information for how to manage the situation

Of the nineteen qualitative studies, seven reported on the benefits of gaining information or learning ways to cope with specific behaviours (Chen et al., 2016; Howard, 1994; Howard, 1998, Knudson & Coyle, 2002; Landon et al., 2016; Poonnotok et al., 2016; Rungreangkulij & Chesla, 2001). In Chen et al.’s (2016) model an initial ‘contemplation stage’ was proposed, with parents ‘considering options’. Here advice was given from various sources around help-seeking decisions and was most commonly provided by health and mental health professionals. Some families used knowledge from family history of mental health service use, and most tended to ask relatives and friends affiliated with mental health services for advice. Most parents followed the advice given and perceived it as helpful. Similarly, Howard
(1994) developed a 4-stage model to describe the experiences of caring for the mothers in their study. The third stage, ‘enduring the situation’ highlights the importance for mothers of knowing ‘what we were dealing with’, and understanding their child’s diagnosis led to parent couples providing more support to one another. In their theme ‘learning, coping and acceptance’ Howard (1998) describes fathers finding specific responses to situations, having learned these from various sources, including ‘informative books and literature’, ‘self-help groups’, and ‘study and discussions with professionals and other families’. In Knudson and Coyle’s (2002) study, parents reported practical advice as one benefit of being part of a support group. Similarly, Landon et al. (2016) described parents learning strategies and skills to manage the situation from self-help groups and education courses. Poonnotok et al. (2016) found that parents searched for information about their child’s illness, which helped them to manage symptoms and find sources of help. They also gained knowledge through direct observation, which helped them to manage psychotic symptoms.

### 3.2.1.2 Engaged versus distanced care

Three qualitative studies found that fathers and not mothers responded to the situation by distancing themselves from caregiving (Chesla, 1991; Osborne & Coyle, 2002; Poonnotok et al., 2016). Although interested in their child’s wellbeing, the fathers in Chesla’s (1991) study were not involved in hands-on care of their ill child. These fathers benefited from distancing themselves from care by appearing relatively unburdened, but missed out on experiencing satisfaction or joy from their son or daughter’s daily progress, being less in tune with subtle changes. The one father in Osborne and Coyle’s (2002) study was described as coping through ‘masculine grief’, distancing himself from his daughter’s illness, both mentally and physically, through
work. When he did give up work and spent more time at home with his daughter, he experienced an increase in pressure and concern. In Poonnotok et al.’s (2016) study, four fathers who found that their children’s symptoms did not improve due to medication non-compliance stopped trying to achieve medication adherence for their child, and instead sought to achieve some normality in their own lives, having ‘accepted a new normal’. Conversely, another group of parents in Chesla’s (1991) study approached the role through ‘engaged care’ and sought to understand their child’s experiences. Seeing caring as an extension of their parental responsibilities, these parents appeared the most satisfied, having found a way to support and protect their son/daughter, yet not be drained. Rungreangkulkij and Chesla (2002) found that mothers provided ‘maternal care’, a response typified by gentle supportiveness. These mothers seemed to incorporate both elements of maternal and distanced caregiving, as they were seen as patient, spoke gently, but also created physical distance between themselves and the situation. They learned that their emotional responses affected the patient’s response and adapted accordingly. One mother in Jung’s (2000) study was able to engage in ‘intense nurturing’ of her child. In Ryan’s (1993) study mothers responded with flexibility and tolerance to difficult and disruptive behaviours, with respondents using phrases such as ‘being careful’ and ‘walking on toenails or eggshells’. This enabled them to achieve a sense of balance or normalcy in their lives. Donnelly (2005) found that participants’ lifestyles revolved around their child’s symptoms and the rhythms it created. In the theme ‘Dancing with the rhythms of symptoms’ the mood of the family home was dependent on the child’s symptoms.

3.2.1.3 Help-seeking

Four studies reported findings related to help-seeking (Chen et al., 2016; Donnelly, 2005; Nyström & Svensson, 2004; Skubby et al., 2015). In Chen et al.’s
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(2016) model of help-seeking, the second ‘action stage’ consists of three stages. During the first ‘help-seeking intention’ phase parents recognized the importance of treatment, which facilitated continued help-seeking. The second phase, ‘securing help’ was helped by their child having insight into their illness and understanding the importance of medication. Help from mental health professionals during transitions was seen as instrumental by parents and they appreciated help from their social network. The ‘service appraisal’ phase suggested that parents appreciated staff actively providing medication information and showing them effective communication strategies. Donnelly (2005) also observed a stage where parents developed an initial awareness of symptom severity, which for their Thai participants emerged once traditional healing methods were not able to stabilise their child’s illness. In their theme ‘help-seeking: moving from traditional to Western modalities’, this shift resulted in closer monitoring of medication and improved adherence. For Nyström and Svensson (2004), help-seeking was reported as requiring fathers to ‘put up with humiliation’, as they found professionals to be disrespectful and even experienced humiliation from them. In their theme ‘finding specialized treatment’ Skubby et al. (2015) found that some parents were directly approached by Early Intervention Services (EIS), but most sought out an EIS, due to inconsistent pathways and parents’ lack of knowledge of available support.

3.2.2 Coping with the meaning of the situation

3.2.2.1 View caring as management/practical support

In addition to distanced care, Chesla (1991) found that some parents used a ‘managed care’ approach to the caring role, treating it like a job, with clear objectives and intervention plans. Children receiving ‘managed care’ experienced ‘remarkable achievements’ in the context of significant disability. However, these parents found
the presentation of their son/daughter’s illness challenging and experienced the caring role as draining and ‘a full-time job’. In contrast, Blomgren Mannerheim et al. (2016) found that the more strategies and goals that parents had in their caring role, the more they described their own health status as being better. Similarly, McAuliffe and colleagues (2014) found that for one parent, keeping busy and trying to make progress in the journey with their child gave them relief from worry. For Nyström & Svensson (2004), the theme of ‘finding an important role as provider of practical support’, represented fathers working through the situation they found themselves in, thereby avoiding unnecessary conflicts with their child and regaining control.

3.2.2.2. Finding new meaning in the caring role

In Poonnotok et al.’s (2016) sub-theme of ‘maintaining caregiving with new perspectives’, parents found that when their child experienced a period of symptom stability they were able to provide care with less emotional distress and maintained hope for their child’s recovery. They found that they let things go and worried less about their child’s future, with some acquiring optimistic views through a ‘reciprocal relationship with their child’. In Jung’s (2000) study one mother attempted to create a new meaning for her own life and a new relationship with her ill daughter. The theme of ‘intricacies of caregiving’ in McAuliffe et al.’s (2014) study represented parents experiencing feelings of steadfast or unconditional love, which helped them to see the positive side of their situation and gave meaning to their caring role. These parents willingly provided care and did not use the word ‘burden’ to describe their experiences. Rather, they found caregiving to be rewarding, especially when their love was reciprocated by their son or daughter.

3.2.2.3. Acceptance
Six of the nineteen qualitative studies found that parents responded to their child’s diagnosis with acceptance. In Chesla’s (1991) theme, ‘engaged care’ parents accepted the limitations of their child, which enabled them to remain supportive of them. All but one of the participants in Howard’s (1998) study suggested that they had accepted their child’s illness. When asked what had facilitated acceptance, responses included: ‘knowledge of the illness’, ‘child’s continued psychiatric help…’, ‘time and realization that problems would not go away’, ‘Christian faith’, ‘hoping for a cure’ and ‘love for my son’. Knudson and Coyle (2002), however, observed a shift in parents coping from problem-focused coping (e.g. engaging child in family activities/hobbies) to emotion-focused coping (e.g. accepting what they can’t change). Acceptance was viewed by parents as having a positive impact on both their own wellbeing and that of their child and was thought to be facilitated by understanding their child’s reasons for withdrawal and by downward social comparison (‘it could be worse’). In Osborne and Coyle’s (2002) study, one father’s acceptance related to accepting his lack of control over his child’s illness. In Pejler’s (2001) theme ‘coming to terms with difficulties’, acceptance of the illness was described as helpful in coping with difficulties. This theme also incorporated focusing on the positives in life, being involved in one’s own interests, and hope for a better life for their child. For Poonnotok et al. (2016), the theme of ‘accepting a new normal’ was identified and thought to be achieved through ‘maintaining caregiving with new perspectives’ and ‘distancing from caregiving’ (mentioned above).

Linked with acceptance, both Poonnotok et al. (2016) and Rungreangkulkij and Chesla (2001) found that Thai parents practiced ‘thum-jai’, an approach from Thai culture related to the Buddhist principle of mindfulness and being in the present moment (Bhikkhu, 2007). In part, thum-jai enables an individual to face unpleasant
situations with calmness and acceptance (Patoomwan, 2001). In their theme ‘maternal response to the child’s symptoms’, Rungreangkulij and Chesla (2001) found the effect of thum-jai for parents was that they were more able to respond to social expectations and could avoid symptoms escalating. For Poonnotok et al.’s (2016) parents, thum-jai was a way that parents were ‘dealing with loss and difficulties’.

3.2.2.4. Positive attitude/Hope

McAuliffe et al. (2014) reported under their theme of ‘coping with enduring illness’ that one successful coping strategy was adopting a positive stance, with a positive attitude seen as ‘essential in coping’. In Pejlert’s (2001) theme ‘hoping for a better life for the son/daughter’ hope was considered a ‘sustaining force’ for parents in seeking ways to improve their child’s life, though remaining hopeful was a struggle. Howard (1994) similarly reported hope as a ‘sustaining factor’ for the mothers in their study, with both hope and acceptance reinforcing the mothers’ determination in providing care.

3.2.3. Coping with the secondary impacts/stress of the situation

3.2.3.1 Self-help groups

Five of the nineteen qualitative studies reported benefits from parents attending self-help groups. For Knudson and Coyle’s (2002) participants, self-help groups alleviated their sense of social isolation. However, parents found it difficult to attend a group early after diagnosis, finding such groups dispiriting or overwhelming at this stage.

For the parents in Landon et al.’s (2016) study, attending support groups was useful early on by providing social support, but later fewer than half were attending regularly, as they were coping better and had gained practical skills in managing their situation. Fathers in Nyström and Svensson’s (2004) study described having the
opportunity to speak with others with a child diagnosed with schizophrenia as a ‘life
saver’. In the theme ‘fathers’ sources of support’, Wintersteen and Rasmussen (1997)
found that fathers tended to become involved with groups/public activities around
mental illness only after they were able to get some resolution to their pain, but when
they did they experienced relief from their burdens. For the mothers in Ryan’s (1993)
study, benefit from support groups was found in sharing their feelings with others
who understood, supporting one another, and maintaining hope.

3.2.3.2. Employment and social interests

The parents in Blomgren Mannerheim et al.’s (2016) study were found to
engage in ‘work-related projects’. These provided control in a context where they felt
out of control, with paid work providing internal development, appreciation, and
stimulation. Work also allowed parents to ‘breathe’ and they were able to adapt their
work to fit around their caring responsibilities. Nyström and Svensson (2004) found
that fathers engaged in work in order to regain control over their life-situation and
‘escape’ the caring role and Ryan (1993) found mothers to use work to ‘get away’ and
maintain a sense of normalcy. Osborne and Coyle (2002) also report ‘work’ as a
method of distancing themselves from the caring role. Wintersteen and Rasmussen
(1997) found that work and hobbies provided opportunities for fathers to deal with
troubled feelings, being used much more by fathers than mothers. Mothers and fathers
both viewed fathers as becoming more active in work and hobbies to relieve tension.
Fathers reported that work and hobbies enabled them to feel good about themselves
without making painful thoughts and feelings public. Blomgren Mannerheim et al.
(2016) also found that parents used hobbies/recreational activities as a coping strategy
through ‘recreational projects’. These allowed parents to have a space for themselves,
as well as social contact and openness about their child’s illness.
3.2.3.3. Seeking social support

McAuliffe et al. (2014) found that being able to talk to professionals about what they were going through enabled parents to get ‘rid of it’. One participant in Osborne and Coyle’s (2002) study spoke of emotional support from her daughter, and described the community psychiatric nurse as ‘extremely helpful’, having built a relationship with her son. In Pejlert’s (2001) study, the theme ‘coming to terms with difficulties’ highlighted the importance of support from relationships within the family and church, as well as support from those in similar situations from ‘the Schizophrenia Association’ and support from nurses. Poonnotok et al.’s (2016) parents were supported financially, emotionally and with information by their spouse, children or partner. Family members or the child with schizophrenia also helped with housework, and health care providers gave emotional and informational support to two participants, which helped them to overcome their caregiving difficulties and to feel comfortable. Some of Knudson and Coyle’s (2002) participants felt well-supported by their social networks, which seemed to be related to whether they had first-hand experience of mental distress. In Skubby et al.’s (2015) study having support from others included ‘emotional support’ from friends and family and ‘helpful advice’ from family members and (eventually) mental health professionals. In the theme, ‘fathers’ sources of support’, Wintersteen and Rasmussen (1997) found that fathers tended to use more private and introspective coping, and were seen as fitting ‘typical’ male stereotypes of being ‘strong’ and dealing with emotions alone. Mothers, on the other hand, tended to use more social forms of coping. Mothers also more often found support outside of the family home or in their extended family.
3.3. Results related to coping from quantitative studies

Here findings from quantitative studies are considered as they relate to the attempts made by parents to manage the situation itself, the meaning of the situation, and the secondary impacts and stress of the situation.

3.3.1 Coping with the situation

3.3.1.1 Prosocial and antisocial coping strategies

Hall and Docherty (2000) and St-Hilaire et al. (2007) both reported on specific coping strategies used by parents to manage the situation, derived from the SACS. Hall and Docherty’s (2000) findings showed that parents with more assertive coping styles were less critical of their child, which the authors suggested may be because these parents are interacting with their offspring in a more constructive manner. Parents with an assertive coping style showed an increase in critical comments when their children presented with aggression. However, Hall and Docherty (2000) made a large number of comparisons (based on nine hypotheses) and risk finding significance where it may not lie. In St-Hilaire et al.’s (2007) study more family history of psychosis negatively related to coping ability in parents. High familial exposure (HFE) parents made less use of overall prosocial coping strategies than low familial exposure (LFE) parents and controls. HFE parents were also less likely than controls to use ‘instinctive action’.

3.3.2. Coping with the meaning of the situation

3.3.2.1 Optimism, Empowerment and Mastery

Greenberg et al. (2004) investigated the relationship between the mother-child relationship and psychological wellbeing and depression in mothers, and the mediating effect of the mother’s dispositional optimism. They found that mothers with higher education levels were more optimistic. Maternal education was related to
better psychological well-being, an effect mediated by optimism. Mothers also had better psychological well-being when the relationship with their child was positive, and this was partially mediated by optimism. Mothers with positive relationships with their child had fewer depressive symptoms, but this effect was fully mediated by optimism. Optimism was related to better mental and physical health. Similarly to optimism, Morin and St-Onge (2015) developed a model in which adaptation can be seen as empowerment and social functioning. They found that empowerment was predicted by the combined effect of the positive aspects of the parents’ experience and their coping strategies. Social functioning was less for parents actively participating in a family association, most likely because these were the parents requiring additional support and intervention. Hobbs (1997) measured coping (as mastery) using Pearlin and Schooler’s (1978) 7-item Mastery Scale. For the mothers in their study, coping and social support reduced depression, with the effect of coping more than double that of social support on depression. Coping mediated the negative effect of physical health on depression.

3.3.3. Coping with the secondary impacts/stress of the situation

3.3.3.1. Coping and social participation

Ghosh and Greenberg (2012) found that social participation significantly predicted lower subjective burden in fathers and significantly predicted fewer depressive symptoms for fathers who reported providing greater instrumental assistance with daily living. Conversely, mothers who provided a lot of assistance experienced greater positive well-being by engaging in fewer social activities. Social participation significantly predicted improvement in psychological wellbeing for both mothers and fathers and employment predicted reduced feelings of burden and improved psychological well-being for mothers only.
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4. Discussion

Findings from the included studies hold implications for how professionals can best support parent caregivers of children with a diagnosis of psychosis, as well as what helps parents to manage this situation themselves. They also highlight some of the potential differences in the ways that fathers and mothers engage in and manage the caring role. Areas for future research are also discussed.

4.1 What helps parents to cope with the caring role?

With regards to parental approaches to caregiving, the qualitative evidence suggests that an engaged, tolerant, loving and gentle approach to caregiving resulted in parents appearing most satisfied with their role and able to learn how to respond to the challenges it brings. However, some benefits were observed in providing care which is goal-oriented, such as improved wellbeing (Blomgren Mannerheim et al., 2016) and enthusiasm for the caring role for parents and progress for the child being cared for (Chesla, 1991). By viewing their role as an extension of parenting, benefits in life-meaning and reduced burden may be experienced (Chesla, 1991). Parents who developed a ‘new perspective’ (Poonnotok et al., 2016) or found ‘new meaning’ (Jung, 2000; McAuliffe et al., 2014) appeared to be more satisfied in their caring role, with a reciprocal relationship with their child being important in these three studies.

Ryan’s (1993) finding that mothers accommodated through ‘being careful’ is similar to the concept of ‘cautious action’. Evidence from quantitative studies suggests that parents with an assertive coping style may be less critical of their child when levels of the child’s aggression are low (Hall and Docherty, 2000). Prosocial coping strategies, such as cautious action and assertive action, have been shown to increase social support and decrease distress in the short- and long-term (Monnier et al., 1998).
For the most part, acceptance of their child’s illness and adjusting their expectations accordingly appears to have a positive impact on parents and their child diagnosed with schizophrenia. However, the process by which parents reach acceptance is not clear, with parents reporting various means by which this was promoted. Knowledge and understanding of the illness and its symptoms may be one aspect which could be facilitated by professionals and was highlighted by Howard (1998) and Knudson and Coyle (2002). In addition, the practice of thum-jai (or associated practice of mindfulness) may be one additional tool by which parents can begin to accept whatever the present moment brings. Greenberg et al.’s (2004) and Morin and St-Onge’s (2015) findings point to the benefits of improving the positive aspects of caregiving in order to promote parental empowerment and optimism.

Related to these ideas is the concept of instinctive action, defined as ‘following one’s own instincts and personal strengths when resolving a problem that is causing stress’ (Hobfoll et al., 1993). Although an antisocial coping strategy, St-Hilaire et al. (2007) suggest that instinctive action may relate to parents having confidence in their own coping abilities as a result of reduced burden and perceived stigma, and Hobbs’ (1997) findings suggest that mastery may play a greater role in reducing depression in mothers than social support.

4.2 Gender and caring

In this review, seventeen studies looked at mothers’ and fathers’ experiences, six investigated those of mothers only (Greenberg et al., 2004; Hobbs, 1997; Howard, 1994; Jung, 2000; Rungreangkulkij & Chesla, 2001; & Ryan, 1993), and two the experiences of fathers of adult children with schizophrenia (Howard, 1998; Nyström & Svensson, 2004). It is interesting to note that in Chesla’s (1991), Osborne and Coyle’s (2002), and Poonnotok et al.’s (2016) studies it was only the fathers that
engaged in ‘distanced care’. This suggests that there may be a difference in the way that some fathers manage having a son or daughter with psychosis when compared with mothers. Chesla (1991) interpreted this finding as a remnant of a time when women were responsible for all parenting tasks and men for work outside the home. They suggest that as these roles change over time, that women may too begin to engage in more distanced care. Wintersteen and Rasmussen (1997) also found that fathers tended to use more ‘typical’ male responses of being strong and dealing with emotions alone, and mothers more social coping. Both Chesla’s (1991) and Wintersteen and Rasmussen’s (1997) findings are presented with caution (see quality assessment). Similarly, the fathers in Howard (1998)’s study were not considered to be the main carers, but gave financially and spent time with their children. However, in Rungreankulkij and Chesla’s (2001) study, mothers’ ‘maternal care’ involved distancing from the difficult situation, indicating that mothers too may use this coping strategy, although it may be more commonly found in fathers.

From the qualitative studies, continuing to work seems to provide parents with a chance to escape their caring role, exert control over an aspect of their lives, maintain some normality, and made them feel good about themselves. However, in Ghosh and Greenberg’s (2012) quantitative study, employment only predicted reduced feelings of burden and improved psychological well-being for mothers. Of the studies that included both fathers and mothers, two found that fathers were more likely to engage with work (Osborne & Coyle, 2002; Wintersteen & Rasmussen, 1997), one that mothers benefited more from work (Ghosh & Greenberg, 2012), and one found benefits to both parents (Blomgren Mannerheim et al., 2016). In terms of reliability of findings, Ghosh and Greenberg’s (2012) study utilised the largest sample size (100 caregiving couples) and therefore offers the most representative findings for
its sample of parents in the USA. However, Blomgren Mannerheim et al.’s (2016) more recent Swedish study offers insight into European parents and is of very high quality. Taken together, these findings suggest at least a shift from mostly fathers engaging in work as a coping strategy to at least both parents doing so. It may even be the case that caregiving mothers are receiving greater benefits from employment than fathers.

As mentioned above, only two of the studies here looked exclusively at coping in fathers (Howard, 1998; Nyström & Svensson, 2004). Although providing useful contributions to our understanding of fathers coping in this context, it still represents the beginning of investigation in this area. Additionally, these studies were based in the USA and Sweden and findings may not translate to men caring in the UK, where both culture and service provision differs. A further two studies of fathers were identified but not included, as they did not report on constructs related to coping (Wiens & Daniluk, 2001; Ghosh & Greenberg, 2009). These were based in Canada and the USA, respectively. As both Howard (1998) and Nyström and Svensson’s (2004) studies were qualitative, findings cannot be generalised beyond the population under investigation. Therefore, there is a lack of evidence around fathers’ experiences in caring for an adult child with psychosis in the UK, particularly related to how they cope.

4.3 Implications for clinical practice

From the qualitative studies, it appears that information on the practical aspects of managing the symptoms associated with schizophrenia is valuable to parents, as well as learning what works on a case-by-case basis. Professionals can support parents by offering accurate information and access to support groups and education courses, as evidence suggests that these skills can be learned and bolstered.
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through these means (Howard, 1998; Knudson & Coyle, 2002; Landon et al., 2016). In addition, professionals can encourage parents to make their own observations and learn how best to respond to their ill child, being experts by experience (Poonnotok et al., 2016; Rungreangkulkij & Chesla, 2001). Taken together, these studies emphasise the importance of parents’ confidence in their abilities or self-efficacy, and how they can be empowered to adapt to their caring role more effectively. They highlight increasing optimism and promoting the positive aspects of caregiving (such as a positive parent-child relationship) as areas for intervention which can improve mental and physical health in parents. Several qualitative studies reported on the positive effect of a reciprocal relationship between parent and child (Poonnotok et al., 2016; Jung, 2000; McAuliffe et al., 2014), and family-based interventions may be particularly important for these families, with Chen et al. (2016) highlighting the appreciation by parents’ of being shown effective communication strategies.

Although not using the most reliable measure of coping, Hall and Docherty’s (2000) findings suggest that positive parent-child interactions may be more likely where the parent has a more assertive parental coping style. It also points towards parents with high familial exposure to psychosis being offered additional support by professionals, being less able to utilise prosocial coping strategies (St-Hilaire et al., 2007). Indeed, as Nyström and Svensson (2004) found, seeking help can result in parents feeling disrespected or humiliated. An understanding of this experience by clinicians can help them to provide a sensitive and non-judgmental approach. Better parental awareness of mental health symptoms and when to seek help, as well as increased knowledge of available services may also encourage early help-seeking. Capturing these parents at Chen et al.’s (2016) ‘action stage’, where the intention to seek help emerges could be a critical point of intervention.
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Benefits from attending self-help groups were reported for all the studies reporting on this finding (Knudson & Coyle, 2002; Landon et al., 2016; Nyström & Svensson, 2004; Ryan, 1993; Wintersteen & Rasmussen, 1997), with benefits in both emotional and practical support noted. However there was some variation in when parents most benefited from attending, with some parents finding groups difficult to attend soon after diagnosis (Knudson & Coyle, 2002; Wintersteen & Rasmussen, 1997), and others finding attendance early on most helpful (Landon et al., 2016). This suggests the need for groups to be available to parents as and when required.

4.4 Strengths and Limitations

This literature review was limited in that there was little consistency in the way that parents’ experiences were explored or measured in relation to coping. Therefore, extracting themes and comparing across studies introduced some subjectivity, despite the use of triangulation through discussions with the two supervisors involved. In part this is due to the complex nature of ‘coping’ and the various ways in which this is conceptualised and framed within models. However, given that so few studies have explicitly sought to investigate parental coping in relation to having a son or daughter with psychosis and fewer still have linked this to coping literature, the current review provides a helpful overview of existing research in the area and highlights the need for further investigation into this population.

The use of Pearlin et al.’s (1990) model to help frame findings provides a context for understanding themes, however the use of any model risks oversimplifying a complex issue and it is important to acknowledge that such models are simply tools to aid our understanding, rather than accurate representations of ‘how things are’.
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Further rigour in the process of quality assessment and data extraction could have been achieved through a second researcher corroborating decisions and a third arbitrator where conflicts arose. However, this was not possible within the context of a doctoral research project.

One strength of the current review is the relatively high number of studies summarised and the incorporation of both qualitative and quantitative research, thus providing a broad representation of the current literature.

Only 4 of the 25 studies included in this literature review exclusively looked at parents of working age caring for a son or daughter with psychosis, with the remaining 21 exploring experiences of parents ranging from working age to over 65. As such, it is not possible to conclude whether any cohort differences exist between carers of different generations, for example whether men of working age in caring roles hold less stereotypical gender role perspectives than their older counterparts (Siyanova-Chanturia et al., 2015).

In conclusion, parents are a valuable resource in providing care for their child with a diagnosis of schizophrenia (Klages et al. 2017) and effective coping enables them to continue in this role. Professionals can support parents by offering accurate information and access to support groups and education courses early on. Professionals should be particularly aware of the need to offer support for parents with high familial exposure to psychosis and aggression in their son or daughter. Family-based interventions that promote a positive relationship between parents and their children and a sensitive, non-judgmental approach from professionals are indicated from this literature review.

Research into intervention programmes will be important to better understand what is most effective and valued by parents. Given evidence from the literature that
men and women experience and respond to the carer role differently (Russell, 2001; Slack & Fraser, 2014; Thompson et al., 2000; Yee & Schulz, 2000), further research into how fathers cope with caring for a son or daughter with psychosis will be useful in enabling a better understanding of ‘what helps’, as well as highlighting areas for intervention in this group.
5. References


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Part 3: Clinical Experience

Year 1

12-month adult mental health placement in a Community Mental Health Recovery Service (CMHRS)
This placement involved working with working-age adults, presenting with severe and enduring mental health difficulties, in a community setting. The placement involved working with complex risk issues and highly sensitive difficulties including: depression, anxiety, panic disorder, psychosis, bipolar affective disorder, borderline personality disorder, a history of traumatic experiences and adjustment difficulties. My responsibilities included assessment (both therapeutic and risk-related), formulation and delivery of individual CBT interventions with this client group. I also ran a weekly CBT-based ‘coping skills’ workshop with another member of the team and ran a group for parents with an adult child with a psychosis-related diagnosis. Intervention models used in included Cognitive Behavioural Therapy (CBT), Compassion Focused Therapy (CFT), Dialectical Behavioural Therapy (DBT e.g. emotion regulation), and Acceptance and Commitment Therapy (ACT). I also conducted a service-related research project, exploring participants’ perceived benefits of attending the coping skills group. Other experience included conducting neuropsychological screening assessments and observing neuropsychological testing on another individual. As part of my placement, I also attended and contributed to Multi-Disciplinary Team (MDT) meetings, NICE guidance development meetings, and business meetings. As part of my teaching and training competencies, I delivered a piece of training to a carers’ group, alongside another trainee, on ‘the Triangle of Care, support for carers, what psychology offers and an introduction to CBT’.

Year 2

6-month Learning Disability placement in Community Learning Disability Team
This placement involved working with working-age adults with (or suspected of having) a Learning Disability, presenting with mild to severe mental health difficulties, in a community setting. My responsibilities included assessment, formulation and delivering individual CBT and behavioural interventions to clients. I also provided indirect/consultation work to carers and staff teams, in relation to anxiety and behaviour that challenges, using systemic and behavioural models and incorporating attachment theory. Assessments, interventions and reports/feedback were adapted to individual needs, taking into consideration the learning disability, communication difficulties and sensory difficulties. In addition, I conducted a sexual knowledge assessment, cognitive assessments to determine eligibility for service, assessments of executive functioning, functional assessments of Challenging Behaviour using the Positive Behaviour Support (PBS) model, and an Autistic Spectrum Disorder (ASD) screening assessment. Much of my work involved joint working with other members of the MDT, including Social workers, Occupational Therapists, Speech and Language Therapists and nurses in order to meet the clients’ needs. As part of my placement, I delivered training with another trainee on ‘the Care Act’ to the MDT. I also attended several MDT meetings, local and Trust-wide psychology meetings, social care reviews, and a safeguarding review meeting for a client I worked with. I also presented a case to the Trust’s ethics committee to explore the least restrictive option for a client in a care home. For my own CPD I attended a
systemic family therapy consultation session, where clients from the LD team were brought for systemic reflection and discussion to aid formulation.

6-month Child placement in a Child and Adolescent Mental Health Services (CAMHS) Team and CAMHS-LD Team
This placement was split between the CAMHS team, working with children and young people (up to the age of 17) and their families, where the child/young person was experiencing moderate to severe mental health difficulties in a community setting and the CAMHS-LD team, working with children and young people and their families, where the child/young person had a learning disability and was also experiencing mental health difficulties. I also spent half a day a week as part of the family therapy team, either as reflecting team member or lead therapist (for one family). The placement involved working with risk issues and sensitive difficulties including: low mood, social anxiety, Generalized Anxiety Disorder (GAD), low self-esteem, self-harm, attachment and relationship difficulties, emotion regulation difficulties, ASD, Attention Deficit and Hyperactivity Disorder, Gender Identity Disorder, eating disorders, challenging behaviour, and traumatic experiences. A range of models were used to inform my assessments and interventions including CBT, narrative therapy, behavioural (parenting) approaches and systemic and attachment theories. Interventions involved working with individuals, families and parent work, and consultation to one care home (Looked-After Child) and schools. I undertook two neuropsychological assessments with children to assess eligibility for the learning disability service, as well as functional behavioural assessments in relation to challenging behaviour for a child under the CAMHS-LD team. I facilitated a workshop for my colleagues on ‘gender and sexuality in young people’, in partnership with a trainee based within a sexual and mental health service. Additionally, I provided supervision to undergraduate psychology placement students and assistant psychologists within the team. I also attended MDT meetings, business meetings, local psychology meetings, team referral meetings, chaired a meeting at a school and attended the CAMHS team away day. In terms of service development I contributed to the development of a ‘coping skills’ group for those children and young people waiting to be seen for individual therapy.

Year 3

6-month Specialist placement – Systemic Family Therapy Service for working age adults
In my specialist placement, I worked as part of a family therapy team with working age adults, primarily referred through Community Mental Health Recovery Services (CMHRS). In this placement I worked as reflecting team member, co-facilitator and lead therapist for adults with a range of difficulties including low mood, anxiety, eating disorders, bipolar affective disorder, psychosis, Borderline Personality Disorder, cognitive impairment as a result of stroke, and complex grief. Relationship difficulties were a common thread throughout all work. Assessments and interventions were carried out in family therapy rooms with the reflecting team behind a screen. My work also included liaising with other services and organisations such as the CMHRS and Social Services. The main model applied on this placement was systemic psychotherapy, incorporating elements of psychodynamic and narrative models and attachment theory. In terms of leadership experience, I led a workshop on the use of reflecting teams outside of family therapy settings as part of the systemic
family therapy forum, which was open to any clinicians within the Trust. I also supported reflective practice groups provided by the family therapy team to other teams within the Trust. Additional experience included attending peer supervision groups, complex case forum, MDTs and business meetings within the family therapy service. I also helped to develop the service leaflet and was involved in responding to a consultation document recommending service closure following a service review. As part of my own CPD, I attended a training day provided by the Association of Family Therapists (AFT) on ‘Systemic ways of talking as an invitation to collaborate’. I also attended a session run by the family therapy team and a service user at the Recovery College, which provided a service user’s perspective of living with mental health difficulties and was attended by service users.

6-month Older Adult placement – Inpatient work on dementia wards and older adult mental health wards, Living Well With Dementia Team, and Memory Assessment Service

In my final placement, I worked with older people (aged 65 and over) primarily with organic issues (Alzheimer’s and other dementias), but also adjustment issues, and challenging behaviour. Work was carried out across a range of settings including an inpatient dementia ward, an inpatient psychiatric ward, a community site, care homes and clients’ homes. Both individual and indirect interventions were conducted using a variety of CBT, systemic, ACT, behavioural, and bio-psycho-social (Newcastle model) approaches. Ideas from attachment theory, grief models and psychodynamic approaches were also incorporated into my work. The majority of cases included close joint working with MDT colleagues including psychiatrists and community psychiatric nurses. In one case I arranged a professionals meeting in order to share information with our colleagues in social services and the care provider, where risk issues were present. My work in the Memory Assessment Service involved co-facilitating a psychoeducation and CBT-informed group for people recently diagnosed with a dementia. Prior to starting the group I completed group eligibility assessments and, afterwards, feedback sessions with attendees. In relation to teaching, I was involved in delivering training around risk assessment and contributed to developing further training around risk factors for physical and verbal aggression in those with a dementia diagnosis. I also developed training for future use on administering a neuropsychiatric screening tool on the wards. In terms of leadership development, I provided consultation to an Occupational Therapist regarding her research project and provided support in running a focus group. I helped to facilitate a reflective practice session for ward staff. As part of service development I developed a ward manager checklist to incorporate the Triangle of Care into new ward admissions, which I produced and presented at a quality meeting for ward managers to trial. A significant part of my work involved direct and indirect neuropsychological assessment and formulation in relation to suspected cognitive impairment, both on the wards and in the community. Following assessment, I wrote summary reports and disseminated results to colleagues, patients and their families, recommending psychological cognitive rehabilitation and behavioural strategies as appropriate. Other experiences included attending the neuropsychological supervision meeting, quality group meetings for the wards, Memory Assessment Service psychology meeting, and contributing to client formulation discussions during ward reviews. In addition, I learned about older people’s experiences outside of the therapeutic relationship by visiting a dementia charity and carers’ support group.
### Year I Assessments

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<tr>
<td>Practice Report of Clinical Activity</td>
<td>CBT assessment and formulation of John (pseudonym), a male in his late 30’s experiencing difficulty understanding his diagnosis of Schizophrenia and anxiety related to voices when out in the community</td>
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<tr>
<td>Audio Recording of Clinical Activity with Critical Appraisal</td>
<td>Audio Recording and Critical Appraisal of Cognitive Behaviour Therapy for Obsessive Compulsive Disorder Session</td>
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<td>Report of Clinical Activity N=1</td>
<td>Cognitive Behaviour Therapy with Exposure Response Prevention with a British man in his Late Twenties presenting with obsessional difficulties and compulsive behaviours in the context of a diagnosis of schizophrenia</td>
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<td>Major Research Project Literature Survey</td>
<td>To what extent has coping flexibility previously been considered in relation to the stresses/challenges experienced by male carers in the caring role? A literature Survey</td>
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<td>Major Research Project Proposal</td>
<td>The experience of working-age fathers providing care to a son/daughter with a psychosis: An exploration of fathers’ accounts of coping.</td>
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<td>Service-Related Project</td>
<td>Clients’ satisfaction with and perceived usefulness of the CBT-based ‘Coping Skills’ group before and after specific changes to delivery.</td>
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<td>Assessment of Learning Disability in a Socially-Isolated Male in his Early Thirties</td>
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<td>Graded Exposure for Social Anxiety with a White British Adolescent Girl</td>
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<td>Report of Clinical Activity</td>
<td>Couples systemic psychotherapy in the context of severe depression with anxiety</td>
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<td>Final Reflective Account</td>
<td>On becoming a clinical psychologist: A retrospective, developmental, reflective account of the experience of training</td>
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