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Exploring factors in parental understanding of early psychosis

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Overview

This portfolio thesis consists of three parts: a systematic literature review, an empirical paper and appendices. The thesis considers the factors influencing the understanding of parents in early psychosis.

Part one is a systematic literature review exploring the factors that influence the experience of stigma of parents of a child with psychosis. The review critically evaluated and synthesised the findings of twelve qualitative papers. The NICE quality checklist was used to evaluate the quality of each paper and Narrative Synthesis was used to synthesise the data. The results demonstrated the wide-reaching effects of stigma. They also highlighted a need to provide caregivers with support, as those with more support had a reduced experience of stigma. The clinical implications of the findings and potential avenues for future research are explored.

Part two is an empirical study of parents' experience of making sense of ARMS through family interventions. Seven parents were recruited and shared their experiences through semi-structured interviews. The data gathered were analysed using Interpretative Phenomenological Analysis. Three superordinate and seven subordinate themes emerged from the data. The findings demonstrated that parents appeared to share a similar experience of sense-making, which continued following their involvement with services. The findings of the study are discussed in the context of previous literature and the implications and recommendations for future research are considered.

Part three consists of appendices relating to both the systematic literature review and empirical paper. This includes a reflective account of the research process and a statement regarding the epistemological position of the researcher.

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Clinical Psychology Review

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The stigma of psychosis:

A systematic literature review of the factors influencing the experience

of parents and caregivers

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Abstract

Purpose: People with a diagnosis of psychosis experience more stigma than those with other mental health conditions. Stigmatising attitudes are also applied to those associated with the person experiencing psychosis. This review is intended to provide an up-to-date, systematic review of the current literature available on the factors that influence how family systems, in particular caregivers, experience stigma of psychosis.

Method: A systematic search of the literature was conducted using four electronic databases: PsycINFO, MEDLINE, CINAHL Complete and Web of Science between August and September 2018 and again in February 2019. Of 3196 articles found, 12 met the inclusion criteria. A narrative synthesis was used to synthesise the data.

Results: The findings from the data were encompassed in two superordinate themes: the external factors influencing stigma and the caregiver's response to stigma. The external factors influencing stigma included five subthemes: interactions with services, the reactions of others, knowledge of psychosis, public image of psychosis and access to social roles. The caregiver's response to stigma included three subthemes: the emotional impact of stigma and the decision of whether to share or conceal the diagnosis from others.

Conclusions: This review demonstrates the wide-reaching effects of stigma on the lives of caregivers. Caring for a person with a diagnosis of psychosis influenced their social opportunity, status, support network and employment opportunities. Caregivers who received support from friends and family experienced less stigma than those who were rejected by others. Furthermore, a considerable impact on the mental health of

caregivers was observed. Taken in conjunction with their limited support system and stigmatising encounters with mental health services, these findings highlight the need to provide more support to caregivers, which in turn may reduce their experience of stigma.

Introduction

Stigma relating to a diagnosis of mental illness is characterised by negative beliefs or attitudes that might exist in particular social, cultural and political contexts (Wong et al, 2009). Stigma is also directed at those associated with the stigmatised person (Goffman, 1963). Stigma directed towards those associated with a stigmatised individual is generally referred to as "associative stigma" (originally "courtesy stigma"; Goffman, 1963). This is known to negatively impact the psychological well-being of family members (Martens & Addington, 2001). It has been said that people with a diagnosis of psychosis are one of the most stigmatised groups in our society (Wood et al, 2015). The increased stigma towards psychosis when compared to other mental health conditions appears to be a result of perceptions that those with psychosis are dangerous, unpredictable and unlikely to recover (Longdon & Read, 2017). In a survey of public perception of mental illness, 61% of respondents suggested that a person with a diagnosis of psychosis was "Very" or "Somewhat Likely" to be violent towards other people (Link et al, 1999, p.1329). Furthermore, caregivers are aware of the beliefs others hold about mental illness. Struening and colleagues (2001, p. 1637) asked caregivers about their opinion of stigma and found that 79% either agreed or strongly agreed with the statement: "Most people think that a person with a serious mental illness is dangerous and unpredictable". The information provided to the public about the cause of psychosis may have contributed to stigma. Initiatives designed to reduce stigma by focusing on a scientific explanation of psychosis have been found to be ineffective and in some cases increased stigma (Longdon & Read, 2017). In contrast, a psychosocial explanation improved attitudes towards psychosis and reduced stigma (Longdon & Read, 2017).

Due to the usual age of onset of psychosis occurring during adolescence, and a move towards community care rather than institutional care, it is common for service users to be living with parents (Addington & Burnett, 2004; Chan, 2011). However, this means that the caregiving role of a parent usually extends beyond the usual timeframe (Carter & McGoldrick, 1989). This is known to lead to concerns from the caregiver about the future of the service user (Van Wijngaarden et al, 2009). The expectation of parents to continue caring for their child with limited resources and limited support available for families, can place considerable pressure on parents (Chan, Yip, Tso, Cheng & Tam, 2009). Understandably, many parents in this position report experiencing burden in their caregiving role and demonstrate high levels of distress (Addington, Coldham, Jones, Ko & Addington, 2003; Fernando, Deane, McLeod & Davis, 2017). However, the primary caregiver is not necessarily a parent, and does not necessarily live with the person experiencing psychosis. Caregivers are shown to experience the same amount of distress and concern even when they live separately (Addington, Addington, Jones & Ko, 2001).

The demands of caregiving, coupled with an awareness of stigmatising attitudes in society, have been shown to impact the mental health of caregivers. One study found that perceived stigma and depression were significantly linked in caregivers (Magaña Ramirez-Garcia, Hernández & Cortez, 2007). Considering that a change in one member of a family's functioning is known to lead to changes in other family members (Bowen, 1966), this can have a considerable impact on relationships within the family and on the family environment as a whole. Furthermore, the environment of service users is known to impact their experience of psychosis (Barrowclough & Hooley, 2003). A stressful interpersonal environment has been shown to increase the frequency and severity of psychosis symptoms and the chance of relapse (Haddock & Spaulding, 2013). Conversely, an environment that fosters an understanding of psychosis and warmth

towards the service user plays a vital, supportive role and can reduce the risk of relapse (Kuipers, Leff & Lam, 2002; Pilling et al, 2002). Whilst this oversimplifies the dynamics between family members, it illustrates the importance of considering the whole family rather than working solely on a one-to-one basis.

The whole family are living with psychosis, so all contribute to the context of the service user. This demonstrates the importance of supporting families throughout the process. Although there has been literature documenting the stigma experienced by caregivers, there has been no systemic literature review conducted. By gathering and synthesising the current literature in this field, it may help to highlight the experiences of caregivers who are caring for a person with a diagnosis of psychosis and therefore understand the factors that may contribute either positively or negatively to this experience and inform support available to them. For this reason, the aim of this review is to provide a rigorous and systematic review of the current literature around the factors that influence caregivers' experience of the stigma surrounding psychosis.

<u>Method</u>

Search Strategy

A systematic search of the literature was conducted using four electronic databases: PsycINFO, MEDLINE, CINAHL Complete and Web of Science between August and September 2018 and again in February 2019. This was to ensure that a wide range of disciplines were covered to increase the likelihood of finding all relevant literature. Prior to the final literature search, a scoping search was conducted to ensure that there were no existing systematic reviews in this area and to help identify key search terms.

Search terms

The search terms from previous reviews were consulted and possible synonyms were considered. After discussion with the secondary researchers (AG, CS & GB), a search protocol was developed outlining the research question, inclusion and exclusion criteria and the agreed search terms. The purpose of this was to ensure the process remained focused, transparent and replicable. The search terms were then reviewed by a third party experienced in conducting literature reviews. The final search terms were applied:

Stigma* OR prejudice* OR attitude* OR discriminat*

AND

Parent* OR caregiver* OR carer* OR mother* OR father*

AND

Psychosis OR "psychotic disorder" OR schizo* or "first episode psychosis" or FEP

Two search limiters were applied when searching the databases to ensure that the articles shown had been peer reviewed, to ensure that articles were of higher quality and that they were written in English. Though enforced to improve the quality of the literature review and for practical reasons, respectively, it is recognised that these limiters increase the risk of introducing bias into the literature review.

Selection Strategy

All papers retrieved using the search terms were then screened by their title to assess relevance and to remove duplicates. If their relevance to the question was unclear, their abstracts, or in some cases the full article, were reviewed. The abstracts of all papers identified from the initial title search were reviewed and the inclusion criteria applied. To be included, papers had to be published in a peer-reviewed journal and with a main focus on the caregivers of those diagnosed with psychosis. This was to ensure that the stigma experiences were specific to psychosis rather than other mental health conditions. Papers were excluded if they were found to be unpublished, research posters, or case studies and if they did not focus specifically on psychosis. Papers using a solely quantitative methodology were also excluded at this stage due to being incompatible with the aim of the research question, which was to explore the experience of parents. It was thought that a quantitative methodology might restrict the stories of parents. Once all results from the search databases had been screened, the full papers that had initially met all criteria were reviewed and compared to the search protocol. Some papers were excluded at this stage. A hand search of the reference lists of all included papers was then completed to look for other papers that may be relevant to the review. The same eligibility criteria were applied to papers that were found using this method. Figure 1 demonstrates a summary of the selection process.

Identification

Records identified through electronic database searching:
(n= 3196)

PsycINFO
= 1420

MEDLINE
= 783

Web of Science
= 630

CINAHL complete
= 363

Records after duplicates removed:
(n= 2140)

Screening

Records screened by title:
(n=2140)

Records excluded:
(n=2080)

Records screened by abstract:
(n=60)

Records excluded based on:
quantitative methodology, duplication
(n=32)

Eligibility

Full articles accessed to assess for eligibility:
(n= 28)

Records excluded based on:
Insufficient focus on parents, insufficient focus on psychosis, insufficient focus on stigma
(n=20)

Articles obtained from hand search of reference lists:
(n=4)

Accepted

Total articles included in review:
(n=12)

Figure 1. Diagrammatic representation of the process of searching for and selecting appropriate articles.

Data Extraction and Quality Assessment

Data from each study deemed to be pertinent to the review question, such as information about participants, methodology, key findings and limitations, were extracted and then analysed for themes (See Table 1 for Data Extraction Table). In order to assess the quality of each study included in the review, the quality appraisal checklist developed by The National Institute for Health and Care Excellence (NICE) for the appraisal of qualitative studies was utilised (NICE, 2012; See Appendix D). The NICE quality checklist comprises 14 questions assessing the design, reliability and rigour of studies. This checklist is designed to assess the quality of studies which collect and analyse qualitative data, and as such used questions which are framed to be appropriate for the variety of qualitative methods. Where a study meets all or most of the checklist criteria, a score of "++" is given. A study that fails to meet some of the checklist criteria but the conclusions are unlikely to alter as a result, receives a score of "+". If few or no checklist criteria were met and this is likely to have altered the conclusions, a score of "-" is given. This quality checklist was selected in the current review because the larger number of questions provides more depth than other checklists available (e.g. CASP and Evaluation Tool for Qualitative Studies) Furthermore, it considers the context in which the study was completed, which other checklists did not. Four studies were also rated by another researcher and discrepancies were discussed until a consensus was reached. A summary table displaying the results of the quality assessment can be found in Appendix E. Two of the papers included in the literature review were mixed methods (Koschorke et al, 2017; Wong, Kong, Tu & Frasso, 2018). After consideration, they were included in the review as the qualitative component was deemed to demonstrate sufficient depth. The quality of the papers was still assessed using the qualitative quality checklist, with sole focus on the qualitative element of each paper.

Data Analysis

The extracted data was then analysed using Narrative Synthesis. Narrative Synthesis focuses on the use of words and text in order to synthesise the findings from multiple studies with a purpose of telling the 'story' of the literature (Popay et al, 2006). This was deemed the most appropriate method of data analysis for the research question, which focused on experience. The Narrative Synthesis was conducted following the guidelines developed by Popay and colleagues (2006). Once each paper had been read, a textual description was written for each to summarise the relevant information and to aid the data extraction process. This aided the process of translating the data as all information was put into the same format which limited the chance of conceptual connections between papers being missed due to different reporting styles. Conceptual models of the relationships between the studies were then developed. This involved grouping together findings that appeared to be similar and then looking for relationships between the groupings, which lead to the development of the final themes which are detailed below. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was followed in the writing of the current review (Moher, Liberati, Tetzlaff, Altman & Prisma Group, 2009).

Results

Overview of Included Studies

In total, twelve studies were included in the current review published between 2003 and 2018 (see Table 1 for an overview of the studies included). Of the included studies, ten were qualitative, and the remaining two used mixed methods. Only the qualitative findings from these papers were included due to the focus of the research focusing on understanding the experience of parents in their own words. Authors used semi-

structured interviews (Baron, Salvador & Loewy, 2018; Koschorke et al, 2017; Krupchanka et al, 2016; McCann, Lubman & Clark, 2011; Paul & Nadkarni, 2017; Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016; Wong, Kong, Tu & Frasso, 2018) or focus groups (Angermeyer, Schulze & Dietrich, 2003; Buizza et al, 2007; González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007; Schulze & Angermeyer, 2003; Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015) for data collection. Participants were recruited using both purposive and emergent sampling, and sample sizes ranged from 8 to 122 (n=259 in total).

Two studies recruited a solely parent sample (Baron, Salvador & Loewy, 2018; Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016), others included other caregivers such as spouses, siblings and children (Angermeyer, Schulze & Dietrich, 2003; Buizza et al, 2007; Krupchanka et al, 2016). Three studies described participants as 'relatives' or 'caregivers' but gave no specific information about their relationship to the service user (González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007; Schulze & Angermeyer, 2003; Wong, Kong, Tu & Frasso, 2018). Of the remaining four studies, three gave information about a percentage of the participants but did not provide details about remaining participants (Koschorke et al, 2017; McCann, Lubman & Clark, 2011; Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015) and the final study included appeared to misrepresent the number of participants (Paul & Nadkarni, 2017). Whilst clear about their sample consisting of parents, Baron and colleagues (2018) were also unclear when reporting the number of participants. Studies took place across a range of countries including America (Baron, Salvador & Loewy, 2018), Australia (McCann, Lubman & Clark, 2011), Belarus (Krupchanka et al, 2016), China (Wong, Kong, Tu & Frasso, 2018), England (Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015), Germany (Angermeyer, Schulze & Dietrich, 2003; Schulze

& Angermeyer, 2003), India (Koschorke et al, 2017; Paul & Nadkarni, 2017), Italy (Buizza et al, 2007), Spain (González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007) and Thailand (Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016).

Quality of Included Studies

The quality of all studies was assessed using the NICE Qualitative Quality Assessment Checklist (NICE, 2012; See Appendix D). All studies were found to be of good quality scoring between 10 and 13 out of 14. In general, researchers gave in depth descriptions of the recruitment and data collection process and outlined the context in which these were conducted.

One area of the quality assessment that no study achieved was describing the role of the researcher (Q5). Though the practical role the researcher played in the data analysis and synthesis was always outlined, no study included a reflection from the researcher about their position, lens or how they may have influenced the responses of participants, and the interpretation of the results. This is a crucial part of conducting rigorous and trustworthy qualitative research (Krefting, 1991). As discussed, some studies did not provide clear descriptions of the participants and several did not outline clear inclusion and exclusion criteria (Baron, Salvador & Loewy, 2018; Buizza et al, 2007; González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007; Krupchanka et al, 2016; Paul & Nadkarni, 2017). This influences the extent to which the sample can be viewed as representative. Overall, the analysis conducted across studies appeared to be rigorous with appropriate steps taken to ensure reliability.

Table 1. Characteristics of reviewed studies.

Author (year)	Location	Method	Participants	Main Findings	Quality Rating
Koschorke et al (2017)	India	Mixed methods – Qualitative aspect used Thematic Analysis	• 36 caregivers (12 male, 24 female) • 51% parents, 25% spouse, the rest were unreported	1. Others finding out – concern that others would notice changes in service user 2. Negative reactions towards the caregiver 3. Caregivers' emotional reaction and feelings about self 4. Manifestations of psychosis 5. Service user reduced ability to meet expectations 6. Negative reactions towards service user	+ +

Baron, Salvador & Loewy (2018)	America	Interpretative Phenomenological Analysis – semi-structured interviews	• 12 parents
			 • 8 female, 4 male
			 • Unclear reporting
				1. Understanding stigma
				  a. Less stigma for other mental health conditions
				  b. Stigma caused treatment delay
				  c. How families navigated disclosure of diagnosis
				  d. How families distinguished between privacy and stigma
				  e. Comparing mental and physical illness
				  f. Lacking information about psychosis
				 2. Coping with stigma
				  a. Finding commonality with others
				  b. Participating in research
					+ +

Krupchanka et al (2016)	Belarus	Thematic Analysis – semi-structured, in-depth interviews	• 20 relatives (8 mothers, 4 fathers, 2 spouses, 2 children, 4 cousins)	1. Challenges in private domain
				  a. In immediate environment
				  b. Life within the family
				 2. Subjective burden and feelings about stigma
				 3. Challenges in public domain
				  a. Concealment of psychosis
				  b. Avoidance of the rest of the family
				  c. Taking full responsibility, sacrificing own personal life
					+ +

Author (year)	Location	Method	Participants	Main Findings	Quality Rating

Wong, Kong, Tu & Frasso (2018)	China	Content Analysis – semi-structured interviews. Then used fragments from transcripts to match up with domains from the Associative Stigma Scale	• 8 caregivers
			• No further detail
				1. Affective
				   a. 47 text fragments matched
				   b. Heightened emotions
				   c. Change in self-image
				2. Behavioural
				   a. 21 matched text fragments
				   b. Actions caregivers took to cope with blame and shame associated
				3. Cognitive
				   a. 19 matched text fragments
				   b. Experiences of discrimination
				   c. Perceived lower social standing
					+

McCann, Lubman & Clark (2011)	Australia	Interpretative Phenomenological Analysis – semi-structured, in-depth interviews	• 20 caregivers (17 female, 3 male)
			• 17 parents, unsure what relation the remaining 3 were
				1. Being open
				   a. With family
				   b. With friends
				2. Being secretive and reducing contact with others
				   a. Fears and experiences of stigma from others
				   b. Denial and blame from others
				   c. Loss of status
				   d. Isolation associated with stigma
				3. Reducing stigma-related burden
				   a. Talk openly
				   b. Be accessible and provide support
				   c. Others to increase their understanding
					+ +

Author (year)	Location	Method	Participants	Main Findings	Quality Rating

Wainwright, Glentworth, Haddock, Bentley & Lobban (2015)	England	Thematic Analysis – in-depth interviews	• 23 relatives (12 mothers, 10 fathers, 1 husband)	1. Parents trying to make sense of diagnosis
				
				2. Fight with the mental health system
				   a. Not involved in the process
				   b. Lack of empathy from services
				3. Is anybody listening?
				   a. Blamed themselves
				   b. Blamed by services
				   c. Concealed the diagnosis for fear of stigma
				4. Relative's coping strategies
					+ +

Buizza et al (2007)	Italy	Content Analysis – Focus groups	22 relatives (8 mothers, 4 fathers, 6 sisters, 3 brothers, 1 husband)	1. Access to social roles
				   a. Loss of friends
				   b. Illness seen as under the service user's control
				   c. Discrimination in work place
				2. Quality of mental health services
				   a. Perceived inadequacy of treatment
				   b. 'quick fixes' without long term support
				   c. Felt they were not involved or listened to
				3. Internalised stigma
				   a. Caregivers held negative beliefs about mental illness and attributed them to their relative
				   b. Ashamed and tried to hide psychosis
				4. Public image of mental illness
				   a. Lack of or negative information spread by media
				   d. Fosters fear and social rejection
					+ +

Author (year)	Location	Method	Participants	Main Findings	Quality Rating

Paul & Nadkarni (2017)	India	Grounded Theory – in-depth interviews	• 14 caregivers
			• Reporting is not clear
			• (7 male, 7 female)
				1. Premorbid acceptance
				   a. Those previously accepted in the family continued to be accepted and supported
				   b. Lack of acceptance led to increase of violence and abuse within the family
				2. Deep sense of responsibility
				   a. Responsibility towards children ensured support
				   b. Despite pressures, most parents did not report burden
				3. Support vs shame
				   a. Those with scientific understanding were more supportive
				   b. Shame increased chances of discrimination
				4. Role fulfilment – role fulfilment ensured acceptance
					+ +

Poonnotok, Thampanichawat, Patoomwan, Sangon (2016)	Thailand	Grounded Theory – in-depth interviews	25 parents (17 mothers, 8 fathers)	1. Facing change of expectations
				   a. Parents felt that their dreams for their child were lost
				2. Caregiving as unavoidable role
				   a. Sense of responsibility
				   b. Feelings of love and sympathy
				   c. Believing in karma
				3. Struggling to manage symptoms
				   a. Maintaining medication adherence
				   b. Monitoring symptoms
				   c. Preventing relapse
				4. Struggling to deal with impact of psychosis
				   a. Dealing with child's poor decision making
				   b. Dealing with stigma
				   c. Loss and difficulties
					+ +

Author (year)	Location	Method	Participants	Main Findings	Quality Rating

González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon (2007)	Spain	Thematic Analysis (inductive) – Focus groups	• 26 family members (6 male, 20 female)
			• 'generally mother, father or siblings' – not specific
				1. Guilt-isolation
				   a. Received blame
				   b. Feeling avoided by others
				2. Ignored in health care
				
				3. Shame and concealment
					+ +

Schulze & Angermeyer (2003)	Germany	Thematic Analysis (inductive) – Focus groups	• 31 relatives
			• No further information
				1. Interpersonal interaction
				   a. Diagnosis reduced social contact
				   b. Discrimination in contact with services
				2. Public image of psychosis
				   a. Aware of stereotypes and perceived them as hurtful
				   b. Public perception of psychosis as dangerous
				   c. Difference between physical and mental health
				3. Structural discrimination
				   a. Poor quality of mental health services
				   b. Wanted more help in crisis situations
				   c. Not treated as being as important as physical health
				   d. Financial burden
				4. Access to social roles
				   a. Barriers to employment
				   b. Difficulties finding a partner
					+ +

Author (year)	Location	Method	Participants	Main Findings	Quality Rating

Angermeyer, Schulze & Dietrich (2003)	Germany	Thematic Analysis (inductive) – Focus groups	• 122 participants (82 female, 40 male) 67 mothers, 27 fathers, 11 wives, 9 husbands, 4 brothers, 4 daughters	1. Interpersonal interaction
				  a. Stigma from professionals
				  b. Did not receive concrete information
				  c. Feeling guilt due to being blamed by others
				  d. Social exclusion and withdrawal
				2. Structural discrimination
				  a. Lack of support
				  b. Injustices in social structures
				3. Public image of mental illness
				  a. Aware of stereotypes
				  b. Lack of information available
				  c. Different approach to physical compared to mental health
				4. Access to social roles
				  a. Stigma as an obstacle to social roles
				  c. Impact on employment
					+ +

Narrative Synthesis

After synthesising the themes from the selected papers, the factors influencing

caregivers' experience of stigma were understood using the following two domains: 1)

External factors influencing the experience of stigma and 2) Caregiver's response to

stigma.

Table 2: Factors influencing parents' experience of stigma: summary of overarching

and subthemes.

Overarching Themes	1. External Factors Influencing the Experience of Stigma	2. Caregiver's Response to Stigma
Subthemes	1.1 Interactions with Services	2.1 Emotional Impact of Stigma
	1.2 Reaction of Family, Friends and the Community	2.2 Privacy vs. Disclosure of Diagnosis
	1.3 Knowledge or Understanding of Psychosis	
	1.4 Public Image of Psychosis	
	1.5 Access to Social Roles	

External Factors Influencing the Experience of Stigma

This theme explores the external factors that influenced how caregivers made sense of

psychosis and the influence of this upon their experience of stigma. The external factors

included the interaction with services, the reactions of others, the caregiver's

understanding of psychosis, the public's perception of psychosis and how psychosis

influenced access to social roles.

Interactions with Services

The relationship with services appeared to impact caregivers' experience of stigma. In several studies, caregivers reported having negative experiences of seeking support from professionals (Angermeyer, Schulze & Dietrich, 2003; Buizza et al, 2007; Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016; Schulze & Angermeyer, 2003; Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015). In one study, interactions with professionals were described as the most stigmatising encounter experienced (Angermeyer, Schulze & Dietrich, 2003). This was illustrated by a conversation among professionals overheard by a parent:

> *"I used to hear nursing staff speak about relatives and you know one comment*
> *was 'well no wonder he's ill, look at the state of his mother', but they don't seem*
> *to realise that the mother's in that state because she's been trying to cope"*
> *(Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015)*

Caregivers mentioned feeling excluded and ignored by professionals (Angermeyer, Schulze & Dietrich, 2003; Buizza et al, 2008; González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007; Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015). Several caregivers felt that mental health professionals lacked empathy or did not appear to want to help the service user. This was perceived to be indicative of the stigmatising beliefs about psychosis held by professionals (González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007; Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015). This was further evidenced by caregivers' perception that professionals perceived psychosis to be 'incurable', so did not appear motivated to help to the best of their ability (González-Torres, Oraa, Arístegui, Fernández-Rivas &

Guimon, 2007). Others were also concerned that services did not appear to focus on long-term support but rather "quick fixes" (Buizza et al, 2007).

The lack of information provided by services was reported as another negative aspect of the relationship (Angermeyer, Schulze & Dietrich, 2003; Schulze & Angermeyer, 2003; Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015). Caregivers held fears and uncertainty regarding the diagnosis but the support and practical advice they sought from services was not always provided. This suggests that for some caregivers, services inhibited the sense-making process.

In contrast, two studies reported positive experiences of services. Poonnotok and colleagues (2016) found two participants (of 25) had received practical information and emotional support from services. Wainwright and colleagues (2015) found that caregivers had experienced open communication and frequent support from services. However, in the case of Poonnotok and colleagues this represented a small percentage of the sample, and the numbers were not quantified by Wainwright and colleagues.

Reaction of Family, Friends and the Community

One of the main factors that impacted the experience of stigma was how others reacted to the diagnosis. This included family members, friends, colleagues and members of the community (e.g. neighbours). In some studies, caregivers reported positive experiences of sharing the diagnosis with friends and family, including receiving financial support, advice and practical help, such as housework (Koschorke et al, 2017; McCann, Lubman & Clark, 2011; Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016). However, the majority of caregivers had experienced negative reactions from those around them due to stigmatising beliefs about psychosis. Many reported a considerable decline in

their contact with family and friends following other members of their social circle learning of the diagnosis. Some reported feeling excluded and that they were being avoided (Angermeyer, Schulze & Dietrich, 2003; Buizza et al, 2007; González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007; Koschorke et al, 2017). However, some caregivers noticed a reduction in their social circle because they were no longer able to work, which, in this case, is reflective of the impact of living with psychosis as a family rather than a consequence of stigma (Koschorke et al, 2017).

Caregivers also either felt blamed, or had been blamed explicitly, by family, friends and members of the community for the diagnosis (Koschorke et al, 2017; McCann, Lubman & Clark, 2011). One parent stated: *"My own family say that it is because I spoiled him"* (González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007). This contributes to caregiver experience of stigma as it illustrates the belief held by others that psychosis is something negative and for which blame needs to be allocated.

Several caregivers feared being stigmatised by those around them (Baron, Salvador & Loewy, 2018, 2018; González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007; Koschorke et al, 2017; McCann, Lubman & Clark, 2011). In one study, nine participants reported that they had experienced stigma but seven of these were unable to recall direct examples (Krupchanka et al, 2016). Furthermore, the same study found that almost half of the participants felt suspicious that others held negative attitudes towards those experiencing psychosis but that they kept them hidden (Krupchanka et al, 2016). Some were so frightened of derogatory comments from others that they felt they had to "live behind closed doors" (Krupchanka et al, 2016). This demonstrates the importance caregivers placed on the opinions of others and the significant impact actual and anticipated stigma had on their lives.

Knowledge or Understanding of Psychosis

Different beliefs about the cause of psychosis, and the way these beliefs influenced the understanding of psychosis, were outlined in the selected papers. Some caregivers doubted that the service user had an illness and interpreted their behaviour as under their control (Koschorke et al, 2017). Other understandings of the cause of psychosis included stressful life events, karma, black magic and parenting styles (Koschorke et al, 2017; Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016). Several caregivers wished that they had more information about psychosis prior to the diagnosis so they could have recognised some of the behaviours associated with psychosis sooner (Baron, Salvador & Loewy, 2018; Koschorke et al, 2017):

"At first I thought that she was doing this all without any reason… so we used to scold her… if I had brought her earlier [for treatment] then something could have been [done to make it] better"
(Koschorke et al, 2017).

The way caregivers perceived psychosis influenced their experience of stigma. In one study, a view widely held by caregivers was that psychosis was '*an illness that no-one should have'* (Koshorke et al, 2017). They mentioned several examples indicative of stigma, such as being excluded or disrespected by others. However, only a few participants expressed feelings of anger about these reactions. The majority of caregivers viewed the negative reactions of others as 'understandable' or a 'natural consequence' of psychosis (Koschorke et al, 2017). In this case, whilst still caring for their child, caregivers held the same stigmatising attitudes towards psychosis as others in their community. Therefore, they did not perceive the negative reactions towards their child as examples of stigma.

Conversely, when caregivers were given a more scientific understanding of the cause of psychosis, they were more understanding and accepting of their child than others who were not (Paul & Nadkarni, 2017). Caregivers who felt mainly sympathy towards their family member appeared to cope better with caregiving and consequently had a reduced chance of experiencing stigma (Paul & Nadkarni, 2017; Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016).

The understanding caregivers had of psychosis prior to having direct experience of it may have also influenced their perception of stigma. In one study, caregivers described having previously held negative stereotypes about psychosis, due to receiving no information prior to contact with services (Baron, Salvador & Loewy, 2018). This implies that caregivers may anticipate stigma from others because they previously held stigmatising beliefs about psychosis.

The understanding some caregivers held of psychosis also dictated their predictions of their family member's future (Krupchanka et al, 2016; Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016). One parent when talking about their child stated *"he has lost his future"* (Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016).

Public Image of Psychosis

Concerns were also raised by caregivers about the lack of information available to the general public about psychosis. Many reported having insufficient understanding of psychosis prior to their child's diagnosis, which caused a delay in seeking treatment. Several caregivers attributed this to the media being the main provider of information about psychosis. They also discussed how the majority of information displayed by the

media was negative (e.g. associated with danger or violence) which was believed to foster fear in the general public, which lead to stigma (Buizza et al, 2007).

Wainwright and colleagues (2015) demonstrated that caregivers felt that the negative information portrayed by the media was partly to blame for the delay in accessing support. Comparisons were also made between how the general public react to physical health problems and how they react to mental health problems (Angermeyer, Schulze & Dietrich, 2003, Baron, Salvador & Loewy, 2018; Schulze & Angermeyer, 2003):

"I think if he had a different illness that was a physical condition, we would have been sharing it more. There's no doubt in my mind"
(Baron, Salvador & Loewy, 2018).

Access to Social Roles

The experience of stigma for several caregivers was influenced firstly, by the impact that the diagnosis had on their family member's life prospects and secondly, by how much importance they placed on these roles being fulfilled. In four studies, participants mentioned their family member being discriminated against in the workplace as a result of their diagnosis and in some cases unfairly dismissed (Angermeyer, Schulze & Dietrich, 2003; Buizza et al, 2007; González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007; Schulze & Angermeyer, 2003). This was interpreted by parents as evidence that employers held stigmatising assumptions about psychosis which consequently inhibited their family member's ability to meet societal expectations. Paul and Nadkarni (2017) found that if the person experiencing psychosis was able to meet the caregivers' expectations of them in terms of employment and marriage, they were more likely to be accepted by the family and the wider community. Consequently they, and their family, experienced less stigma. Conversely, those that were unable to meet these roles experienced more stigma and were less accepted by caregivers:

"If he is an earning member then I can give him the decision-making…. but he is
jobless, so how can he make decisions?"
(Paul & Nadkarni, 2017)

Caregiver's Response to Stigma

Stigma was also found to be influenced by internal factors linked to the individual

interpretation and approach of caregivers. This included the emotional impact of the

diagnosis, as well as their decision to share the diagnosis with others or to conceal it.

Emotional Impact of Stigma

Caregiving also appeared to have a considerable impact on the mental health of

caregivers. Koshorke and colleagues (2017) reported that caregivers felt "sad" and

"hopeless". Furthermore, they found that 5 of their 36 participants had contemplated

suicide, demonstrating the distress experienced by caregivers. There were also studies

that found caregivers experienced a great deal of guilt over the development of

psychosis, believing they caused it in some way, or guilt over failing to seek help sooner

(Krupchanka et al, 2016; Wainwright, Glentworth, Haddock, Bentley & Lobban, 2015).

"I just feel that I have made some mistake"
(Krupchanka et al, 2016)

Alternatively, some caregivers felt a great responsibility to care for their family member

(Paul & Nadkarni, 2017; Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016).

Poonnotok and colleagues (2016) found that caregivers felt love and sympathy towards

the service user for what they were going through. Equally, they found that caregivers in their study found it easier to maintain hope and encouragement if there were signs of improvement or if their love was reciprocated. Paul and Nadkarni (2017) found that due to the deep sense of responsibility to care for the service user, most did not perceive it as a burden.

<u>Privacy vs Disclosure of Diagnosis</u>

Another topic frequently discussed across papers was whether caregivers decided to share the diagnosis with others. The majority of caregivers across papers made the decision not to share the diagnosis with those around them. Some caregivers did not disclose the diagnosis in an attempt to protect their family member. This was both from the direct stigma of others but also the negative consequences it may have on their life in terms of access to work (Baron, Salvador & Loewy, 2018; Koschorke et al, 2017; McCann, Lubman & Clark, 2011; Poonnotok, Thampanichawat, Patoomwan & Sangon, 2016; Wong, Kong, Tu & Frasso, 2018):

> *"it's definitely a little better for my daughter. The fewer people know about it, the better" (Wong, Kong, Tu & Frasso, 2018)*

Some caregivers went to great lengths to reduce the chance of others finding out. This included withdrawing from family, friends and neighbours and becoming more secretive (Krupchanka et al, 2016; McCann, Lubman & Clark, 2011; Wong, Kong, Tu & Frasso, 2018). Caregivers were also apprehensive of the impact it would have on the whole family. Some were fearful of the impact it may have on their other children, but were also fearful of the impact it may have on the status of the family (Baron, Salvador & Loewy, 2018). Koschorke and colleagues (2017) reported that many caregivers felt that the diagnosis brought 'dishonour' to the family. This added to their distress and

contributed to their decision not to tell others about the diagnosis. However, it also prevented them from seeking help:

"I'm still reluctant to talk about it casually or to talk about when it's a situation where it might, you know, cause negative impressions of her. And of us too, it even comes back to us"
(Baron, Salvador & Loewy, 2018)

This suggests that the primary reason for withholding the diagnosis from others was a result of anticipating negative reactions from them. Caregivers believed that others would view their family member or their family in a negative way as a result of the diagnosis and felt compelled to hide it in order to avoid this. Some reported experiencing shame about their family member's behaviour and appearance (Buizza et al, 2007; Koshorke et al, 2017; Krupchanka et al, 2016). Sometimes this presented as the caregiver trying to make their family member look 'normal' when out in public to prevent others learning of the diagnosis (Krupchanka et al, 2016). However, some caregivers decided to withhold the diagnosis from others not for fear of stigma, but out of respect for the service user (Baron, Salvador & Loewy, 2018):

"Not a shame thing, but a privacy thing."
(Baron, Salvador & Loewy, 2018)

There were also a number of caregivers who were more open to sharing the diagnosis with others and who had found benefit in this. Some found the community to be accepting of the diagnosis and felt it necessary to inform others in order to elicit help (Koschorke et al, 2017; McCann, Lubman & Clark, 2011). Others were of the opinion that it was important to be open about the diagnosis in order to help to reduce stigma in

the wider population (Baron, Salvador & Loewy, 2018). Being open and having family and friends to turn to for support was reported by caregivers as a way of reducing stigma (McCann, Lubman & Clark, 2011). This suggests that attempting to avoid stigma by withdrawing from family and friends may increase caregivers' experience of stigma as they are unable to have open conversations about it or to receive support from others.

<u>Discussion</u>

The aim of this review was to explore the key factors associated with how parents and caregivers of those with psychosis experience stigma. The factors identified in the included studies appeared to fall under two broad themes: the external factors influencing the experience of stigma and the caregiver's response to stigma.

Caregivers experienced stigma both from people in their local community and on a wider, societal level. Different factors within the immediate community of caregivers had an impact on their response to and experience of stigma. For example, caregivers experienced stigma from the people around them as well as from their contact with mental health services. This influenced the emotional impact of the diagnosis as those who observed the negative attitudes of others were more likely to be isolated and feel more distressed. Similarly the reactions of others influenced how they made sense of psychosis as well as their decision of whether to share the diagnosis with others. Caregivers also believed that the public image of psychosis and the information available influenced the attitudes of the community surrounding caregivers, as well as caregiver's own attitudes. The public image of psychosis included the predominantly negative portrayal of psychosis in the media. Caregivers also described feeling that the stigma surrounding psychosis appeared to influence access to social roles, such as

marriage or occupation. How able the person experiencing psychosis was to meet the expectations their caregiver held for them regarding life goals, like marriage and work, influenced how accepting the caregiver was of them and consequently reduced the amount of stigma experienced by the caregiver. Many caregivers cited incidents of wrongful dismissal due to psychosis, which they believed to be the result of negative stereotypes held by managers and colleagues, or a lack of understanding (Buizza et al, 2007; González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007; Schulze & Angermeyer, 2003). Additionally, some caregivers mentioned that other families refused to marry into their family as a result of their child's diagnosis. However, there appeared to be a cultural component to some of the expectations parents had of their child. For example, the importance of marriage and fears that their child would not marry were only raised in the two studies conducted in India (Koschorke et al, 2017; Paul & Nadkarni, 2017).

One further observation was that concerns about the negative public image of psychosis were only raised in western countries (America, England, Germany, Italy and Spain). It is possible that there is more discussion of mental health and associated diagnoses in western media than elsewhere. Conversely, as suggested by Koschorke and colleagues (2017), it could be that parents in other cultures may agree with the negative attitudes of the public and consequently do not perceive these beliefs as stigmatising. Another observed difference between cultures was variation in the type of treatment available for service users. Some studies mentioned that the treatment protocol of the country in which they conducted the research still utilised admittance to institutions as the primary treatment option. This was not the case in other countries such as England, Australia and America. It is likely that there are further cultural differences between the studies, however, the different studies all reported relatively consistent themes. Although,

literature suggests that despite the fact that similar domains are usually affected by stigma cross-culturally, the nature of the stigma varies widely (Van Brakel, 2006).

The reaction of friends, family and the community to a diagnosis of psychosis also influenced stigma experience. Caregivers who had found others who responded supportively to the diagnosis, experienced less stigma than those who had been ostracised or directly discriminated against. Interestingly, one study highlighted that nine participants had reported experiencing stigma but seven were unable to provide examples (Krupchanka et al, 2016). This could be the result of caregivers simply being unable to remember an exact example or could suggest that they held some internalised stigma and expected the same from others. Furthermore, parents appeared to place value on the opinions of others. In an attempt to avoid anticipated or actual stigma, several caregivers avoided social opportunities and lived 'behind closed doors'. Avoiding social opportunities may have contributed to their experience of stigma. Some caregivers who disclosed the diagnosis to others found them to be supportive and consequently experienced less stigma. However, there were many caregivers who had been rejected by family and friends as a result of the diagnosis, therefore reducing their support and increasing their experience of stigma.

Furthermore, the information provided to caregivers influenced their understanding of the diagnosis and also the care they provided to the service user. One of the selected papers highlighted that caregivers who were given a scientific understanding of psychosis showed more empathy towards their children and were more understanding of some of the behaviour that was associated with the diagnosis (Paul & Nadkarni, 2017). Caregivers who believed that the condition was under the control of the service user were considerably less understanding. Conversely, a very literal understanding of

psychosis as being out of the service user's control could also contribute to stigma of unpredictability and consequently, dangerousness. Considering that a large proportion of caregivers across studies felt blamed by others for the service user's diagnosis, it could be that a scientific understanding of the condition is preferred as it removes the blame from caregivers and from service users. It is possible that the discrimination experienced by caregivers from services could be the result of professionals favouring different models for understanding psychosis (e.g. that social factors such as childhood and attachment contribute to its development) which may unintentionally imply blame either to the individual or to their family (Kuipers, Onwumere & Bebbington, 2010).

Considering Bronfenbrenner's Ecological Systems Theory (1979), which demonstrates the influence that the different systems have on an individual, it is possible that caregivers of those with psychosis hold some internalised stigma. Bronfenbrenner's theory would suggest that caregivers' beliefs would be influenced by their immediate environment (e.g. friends, family, neighbours etc.), the wider community, and the beliefs held by society as a whole. With this principle in mind, many caregivers mentioned that the general public hold negative beliefs about psychosis and experienced similar opinions from their friends, family and the local community. Prior to their family member's diagnosis it is possible that they, too, held these stigmatising beliefs about psychosis. Some caregivers even explicitly mentioned having held these beliefs about psychosis prior to gaining more knowledge. This suggests that parents may be navigating a difficult adjustment process as they need to make sense of their child's diagnosis as well as navigating a change to their belief system. Stigmatising beliefs can also be internalised by caregivers which has been shown to have a negative impact on their self-esteem (Link et al, 2001).

An important aspect of the experience of stigma from the findings was the strain that appears to be placed on caregivers. Several studies highlighted the impact that caregiving placed on the mental health of caregivers. In the majority of studies (n=8), caregivers expressed feeling hopeless, isolated, helpless, afraid and ashamed. Furthermore, Koschorke and colleagues (2017) reported that five caregivers out of thirty-six had contemplated suicide. When this is taken in conjunction with a reduction in their support network, discrimination from services and a reduction in social opportunity, it suggests that caregivers are a vulnerable population. This is also suggested in other literature discussing caregiver burden and the lack of support available to caregivers of people with psychosis (Askey, Holmshaw, Gamble & Gray, 2009; Boydell et al, 2014). Further research exploring caregiver burden in parents of those experiencing psychosis could help to gain a better understanding of this issue.

Assessment of Strength of the Review

The assessment of the quality of the included papers demonstrated that the included studies were of a high standard. However, none of the papers defined the role of the researcher clearly. Considering the substantial influence the researcher can have on the data, it is possible that this may have influenced the findings of the included studies. However, the similarities in findings between the studies may suggest that this oversight did not influence the findings too significantly. Eleven out of twelve studies showed appropriate rigour in data analysis and results were checked by multiple researchers. Furthermore, the included studies were conducted across eleven countries which provides interesting comparison between parents cross-culturally. However, there are no more than two studies conducted in any given country which limit the generalisability of the findings to the country of origin.

The strength of the review may also have been affected by variation in how the sample of each study was reported. Some studies were unclear about the included sample, others included relatives with no clear indication as to whether they occupied a caregiving role. The experience of a relative who is not involved in the caregiving process may be different from the experience of someone who is involved in their care. As a result, this limits the strength of the findings of the review and means that confident conclusions cannot be drawn.

Due to the triple hermeneutic created in the process of reviewing qualitative research (Weed, 2005), the synthesis of the findings will have also been influenced by the characteristics of the first author. Clear differences have been found cross-culturally regarding the understanding of psychosis and the attitudes towards it (Mirza, Bitel, Pyle & Morrison, 2019). Consequently, being a White-British female, raised within a western culture will have inevitably shaped the interpretations made by first author. This first author partook in a reflexive interview with supervisors in order to gain a better understanding of some of the cultural assumptions which may impact her lens. Furthermore, a reflective journal was utilised to attempt to hold these assumptions in mind with a view to limit the influence of personal assumptions on the synthesis of findings.

Wider Implications

This review has demonstrated the considerable impact that stigma has on the caregivers of those with psychosis across multiple areas of their life. It has highlighted that during the time of receiving the diagnosis and the adjustment period that follows, caregivers are vulnerable; often receiving little support from those around them and failing to feel supported by services. This highlights the importance for those working in mental health settings, firstly, to be aware of the vulnerability of caregivers during this time and

secondly, to be mindful of their own beliefs about psychosis and how this may influence the sense-making process of caregivers.

The effect of stigma on caregivers will also influence their relationship with the service user. Research has clearly highlighted the influence of those in the immediate environment of a service user and the influence this has on relapse rates and medication adherence (Barrowclough & Holley, 2003; Haddock & Spaulding, 2013). Furthermore, caregivers across studies expressed frustration with services due to not being involved or not being listened to. This demonstrates that supporting a person with psychosis alone is insufficient, instead they need to be considered as part of a wider context. Caregivers play a vital role in supporting people with psychosis, so should be involved in the process and offered individual support. Further research could explore whether there is a relationship between the experience of stigma and the amount of support being offered to caregivers to seek to establish whether more support could reduce the impact of stigma.

The findings also illustrate the need for education on a wider, societal level. Several studies discussed the negative media portrayal of psychosis and its influence on the public perception of psychosis. Over half of the studies had experienced the stigmatising beliefs held by others. While campaigns focusing on a scientific explanation of psychosis can reduce blame placed on those experiencing psychosis, they ultimately promote the "us and them" narrative, which highlights difference (Longdon & Read, 2017). Ultimately, Longdon and Read (2017) suggest promoting mental illness as "an understandable response to adversity" in order to cultivate acceptance and compassion.

Conclusion

There is considerable stigma surrounding psychosis which also extends to those associated with a person experiencing psychosis. The amount of stigma experienced by caregivers is influenced by several factors: the support available, the opinions and reactions of others, the caregiver's understanding of psychosis, their emotional response and the ability of the service user to meet societal expectations. Caregivers who gained support from family and friends experienced less stigma than those who received less support. Equally, those who agreed with the negative beliefs others held of psychosis also perceived less stigma. The part that professionals play in caregivers' experience of psychosis was also illustrated. The findings highlight the considerable stress that parents and caregivers experience whilst caring for someone with psychosis. Education on a public health level and an increase in the support offered to caregivers may help to reduce stigma and caregiver burden in the future. However, due to the lack of clarity in how included studies reported their sample, the findings should be interpreted with caution.

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* indicates articles included in the literature review

Part Two: Empirical Paper

This paper is written in the format ready for submission to the journal

The International Journal of Qualitative Studies on Health and Wellbeing

Please see Appendix F for the submission guidelines

An interpretative phenomenological analysis of parents' experience of making sense of at risk mental state through family interventions

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Abstract

The concept of At Risk Mental State (ARMS), that is people deemed at elevated risk of experiencing a first episode of psychosis, is contested in the literature. Early intervention for ARMS can reduce distress and improve prognosis, however there are concerns about the reliability and validity of the concept. Family interventions are recommended for people meeting the ARMS criteria. How families make sense of problems influences their emotional experiences and relationships. To date there has been no research exploring how parents make sense of ARMS. Seven parents with a child meeting the ARMS criteria shared their experiences through semi-structured interviews and the data gathered were analysed using Interpretative Phenomenological Analysis. The findings suggested that parents experienced three stages when making sense of the ARMS criteria consisting of initial uncertainty, experience of getting support and the process of looking to the future. This research offers an understanding of the experiences of parents at different stages during their involvement with services. It illustrates that this journey through sense-making appeared to be shared by all participants included in this study. Future work could consider ways of including and supporting parents during this sense-making process.

Introduction

Early intervention in psychosis has been associated with a reduction in unshared experiences and a higher recovery rate, at a lower cost (Mihalopoulos, Harris, Henry, Harrigan & MGorry, 2009). With this in mind, the At Risk Mental State (ARMS) criteria were developed in an attempt to identify those with increased risk of experiencing first-episode psychosis (FEP) in order to enable even earlier intervention (Yung, Phillips, McGorry & McFarlane, 1998). The early indicators identified included experiences associated with anxiety or depression, sleep disturbance and transient experiences of seeing, hearing or believing things that others do not (Thompson, Marwaha & Broome, 2016). It was thought that the ability to identify this 'at risk' population and offer early intervention might prevent FEP. In their research, 40% of a population identified as meeting the criteria had experienced an episode of psychosis within six months (Yung, Phillips, McGorry & McFarlane, 1998). It is currently estimated that of those meeting the ARMS criteria, 20% will go on to experience FEP, compared to the 40% previously suggested (Fusar-Poli et al, 2018). Previous research has argued that this reduction is evidence of the success of early intervention; however, randomised controlled trials have found no significant difference between the number of people who went on to experience FEP in the cognitive therapy condition when compared to controls (Lin, 2017; Morrison et al, 2012). This decline calls into question the clinical utility of identifying an 'at risk' population and suggests that the criteria may lead to a number of false positives (Fusar-Poli et al, 2018; Os & Guloksuz, 2017). Furthermore, there is considerable debate regarding the existence of 'psychosis' as a diagnosis, casting further doubt on the ARMS criteria (Bergström et al, 2019).

However, early identification and early intervention have had some effect on reducing the frequency and severity of unshared experiences, as well as reducing distress

(Morrsion et al, 2012). Furthermore, for some, meeting the ARMS criteria was perceived to be a valuable and normalising experience (Welsh & Tiffin, 2011). A recent study reviewing the experience of people meeting the ARMS criteria found that they were relieved that a specific term was applied as it made sense of the changes they had observed (Uttinger et al, 2018). It is recognised that there are ethical issues in providing these individuals with any label as, aside from the potential impact on an individual's sense of self, they do not meet the criteria for any diagnosable condition. The conflicting opinions on the utility of the ARMS criteria and the fact that experiencing a FEP is not inevitable will likely have an impact on how the individual and their families make sense of meeting the ARMS criteria.

Davis, Nolen-Hoeksema and Larson (1998) define sense-making as the process of attempting to understand a significant situation by finding the way it fits with one's current worldview or cognitive schema. Sense-making is a central human process and plays a pivotal role in the adjustment process (Pakenham, 2010; Weick, Sutcliffe & Obstfeld, 2005). It has also been associated with better adjustment in parents of children with disabilities (Behr & Murphy, 1993). With regard to psychosis, Klapheck and colleagues (2014) found that in a sample of individuals with unshared experiences, 80% felt a need to assign a meaning to their experiences, with psychosis being just one possible meaning. Furthermore, in a study which focused on how young people make sense of FEP, Geekie (2013) found that the process of telling their story helped them to make sense of their experiences.

Due to the usual age of onset of unshared experiences being between approximately 14 and 30 years of age, a large proportion of those in the early stages of psychosis are often living at home with parents or caregivers. One could assume the same could be said for those meeting ARMS criteria (Addington & Burnett, 2004). As a result, families are

also living with these experiences and are more likely to be involved in the treatment process (Addington & Burnett, 2004). One of the main concerns for family members of those who meet criteria for FEP is that they do not understand psychosis but often have a detailed understanding of the stigma that surrounds it (Franz et al, 2010). A recent study found that parents of those meeting the ARMS criteria had also experienced stigma (Baron, Salvador & Loewy, 2018). Equally, when a child receives a diagnosis of a mental health condition, it influences parents' perception of their parenting ability as well as leading them to feel undervalued (Jones, 2009; Macgregor, 1994).

Furthermore, the family environment is known to have a considerable effect on relapse rates, stress and an individual's experience (Cutting, Aakre & Docherty, 2006; Haddock & Spaulding, 2013). Consequently, family interventions (FI), an intervention involving the whole family unit, have received a substantial amount of support in the literature (Pitschel-Walz, Leucht, Bäuml, Kissling & Engel, 2001; Dixon & Lehman, 1995). FI aims to improve the well-being of individuals by supporting families so they are better equipped to manage difficulties as they arise, as well as working to improve the well-being of the carer by helping to reduce their stress (Reus et al, 2016). FI have been shown to improve medication adherence, engagement with services and reduce the likelihood of relapse (Pharoah, Mari, Rathbone & Wong, 2010). Moreover, as the service user, family and professionals co-construct an understanding of their experiences that makes sense to the family, stress and tension within the family noticeably reduces (Barrowclough & Tarrier, 1997). Involvement of the family can also help in the early recognition of changes in the individual commonly associated with psychosis, as well as improving the wellbeing of the caregivers (Jones, 2009).

Aside from the impact the family have on medication adherence and engagement with services, warmth and higher levels of emotional support from caregivers have also been

associated with improved outcomes for those at risk of psychosis (O'Brien et al, 2006). This demonstrates the importance of supporting parents to better understand their child and the reasons for their behaviour, as their understanding will likely influence the therapy journey and outcomes. Furthermore, this could provide useful information about the kind of support that would be most appropriate for the family.

FI is now the recommended intervention for those meeting the ARMS criteria and their families (NICE, 2014, p.257). However, at present there has been no research on families' experience of FI for ARMS and the sense-making process. Previous literature exploring the experience of parents of those with a diagnosis of psychosis found that FI helped them to make sense of the diagnosis and treatment pathway as well as improving communication within the family (Nilsen, Frich, Friis, Norheim & Røssberg, 2016). However, the ARMS treatment pathway is less clear as between 60% and 80% of those meeting the criteria may never go on to make the transition to psychosis. For this reason, the aims of the current study are to gain an understanding of parents' experiences following FI and the impact it might have on sense-making in the family. The decision to interview parents is a result of literature suggesting that receiving a diagnosis of psychosis affects the wellbeing of parents most significantly (Addington, Addington, Jones & Ko, 2001). Parents are also known to take on significant roles in caring for service users, which often result in reports of considerable burden and often with limited support from services (Chan, 2011). The current study hopes to gain an understanding of the experience of parents in order to develop this under-reported narrative with a view to understanding how services might better support parents.

Method

Design

The study employed a qualitative approach in order to explore the experiences of participants. Qualitative data were generated via semi-structured interviews which were designed to encourage participants to speak openly about their experiences by acting as a prompt rather than something to be strictly followed. As the primary focus of the study was to examine the lived experience of parents, Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) was deemed the most appropriate approach. IPA aims to explore, in detail, how a person makes sense of the world around them through listening to the way in which they tell their story (Smith & Osborn, 2004). IPA also recognises the context within which the data is generated and the influence that the researcher can have on the interpretations attained (Reid, Flowers & Larkin, 2005). IPA therefore informed both the interview process and the analysis of the results.

Research Question

How do parents accessing family interventions make sense of ARMS?

Participants and Recruitment

Ethical approval was granted from the UK NHS Ethics Committee (See Appendix L). Seven participants (six female, one male) took part in the study. All participants identified as White-British. Participant pseudonyms, the age and gender of their child and the number of FI sessions attended is provided in Table 3. Purposive sampling was used in an attempt to recruit an appropriately homogeneous population. All participants were recruited from Early Intervention Services (EIS) in the local area provided the following criteria were met:

1) ARMS must have been defined by the Comprehensive Assessment of At Risk Mental States (CAARMS; Yung et al, 2005) or the Scale of Psychosis-risk Symptoms (SOPS; Miller et al, 1999)

2) FI must have been delivered by practitioners who have attended a FI course which is recognised by Health Education England (HEE) in line with the recommendations of Early Intervention for Psychosis Network (Chandra, Patterson and Hodge, 2018)

3) Must be a parent of an individual who has been identified as being at risk of developing psychosis

4) Must have attended at least three FI for ARMS sessions so that they have had enough experience of FI to discuss during the interview

5) Must have been able to give informed consent

Participants were excluded based on the following criteria:

1) If they lacked sufficient English fluency

2) If several FI sessions had been missed

3) If their child had gone on to experience FEP

Table 3: Participant pseudonyms, information about their child and the number of FI sessions attended**.**

Pseudonym	Gender	Child's Gender	Child's Age	Number of FI sessions
Jonathan	Male	Female	15	5
Julie	Female	Female	17	5
Charlotte	Female	Female	15	7
Debbie	Female	Female	17	3
Karen	Female	Male	20	7
Joanne	Female	Male	16	6
Carol	Female	Female	17	3

Procedure

Potential participants were initially contacted either by their Care Coordinator, Family Intervention worker or team Psychologist to discuss the purpose of the research. Participants were provided with an information sheet (Appendix G) about the research following the initial expression of interest and were asked if they would mind being contacted by the researcher. Those still involved with the service were provided with information about the research during routine appointments. Potential participants discharged from the service were contacted over the phone and the team member who contacted them posted the information sheet. Ten participants were approached in total, seven expressed an interest. After expressing an interest in the study, the researcher waited 48 hours before contacting potential participants to allow time to consider their participation. They were then contacted by the researcher who was available to answer any questions about the study and an interview was arranged with those wishing to take part. Six out of seven participants chose to complete the interviews at their homes, one participant chose to meet at the EIS.

Upon meeting, participants were given the opportunity to ask questions about the research and were asked to complete an informed consent form (Appendix H). The lead researcher conducted all interviews and followed a semi-structured interview schedule (Appendix I). A Research Involvement Group composed of service users and carers reviewed all documents provided to participants, including the interview schedule. Changes were made to these documents in line with the suggestions offered by the group. Once the interview was completed, participants were given a support sheet (Appendix J) which contained contact numbers and websites that could offer support following the interview, should they require it.

Interviews were completed over a period of six months and were audio recorded on an encrypted laptop. Interviews lasted between 50 and 92 minutes (mean = 64). Each interview was then transcribed. Each participant was given a pseudonym and any potentially identifiable information was removed to retain anonymity.

Data analysis closely followed the guidance of Smith and Colleagues (2009):

1) Transcripts were read several times to ensure familiarity with each interview

2) While reading, initial thoughts and observations were noted

3) Each transcript was examined line by line and comments were made

4) Emerging themes and patterns within the transcript were identified

5) Sections of three transcripts were discussed with secondary researchers (AG, CS & GB) to discuss comments. This also encouraged self-awareness and reflection

6) Comparisons were made between transcripts to identify potential similarities or differences between participant accounts

7) Tentative codes were developed and supporting quotes were compiled from each transcript. The transcripts were reread at this point to ensure that the codes were reflective of the data and ensured that the codes were representative of all transcripts rather than over or underreporting the contribution of certain participants

8) Different ways in which the codes might fit together were explored

9) The final superordinate and subordinate themes were developed. This process was also aided by discussion with secondary researchers (AG, CS & GB) to ensure they clearly and accurately described the data and that they could not be organised differently.

The process of data analysis is evidenced in Appendix K.

Researcher's Position

As IPA involves double hermeneutic interpretation, it creates a paradigm where the researcher is trying to make sense of the process of a participant trying to make sense of the world (Smith & Osborn, 2004). Consequently, the experiences, values, beliefs and background of the researcher affect the interpretation of data and the development of themes to some extent. Considering all participants included in the study were White-British, the researcher also being White-British could mean that the researcher is blind to potential interpretations associated with this, for example, assuming participants will have had a similar experience as herself. The researcher is the younger of two siblings from a close family in which open communication has always been valued. Family

played a considerable role in her upbringing, where beliefs that family were the priority and could be relied upon were embedded. This may have an influence on her draw towards family interventions as a model and may lead to assumptions about what coming together as a family would be like for others. The researcher's personal experience of a family member being identified as at risk of a physical health condition meant that she had some insight into the experience of being in a family that is making sense of an increased risk without the certainty of a diagnosis. This will have an influence on the researcher's expectations of how parents might make sense of the ARMS criteria. A reflexive interview was conducted with research supervisors (AG & CS) to aid the researcher's awareness of these potential biases and a reflective journal was utilised throughout the process (prior to and following interviews) in order to help keep this lens in mind. A more detailed account of the epistemological position of the researcher can be found in Appendix B.

Results

Eight subordinate themes emerged from the interview data, which depicted how parents made sense of ARMS. The eight subordinate themes were encompassed by three superordinate themes, which detailed the different stages of sense-making that parents appeared to experience. These were: 'initial uncertainty', 'getting support' and 'moving forward'. The superordinate and subordinate themes are presented in Table 4.

Table 4: Superordinate and subordinate themes illustrating the sense-making process of parents.

Superordinate Themes	Subordinate Themes	No. of Participants Contributing
1. Initial Uncertainty: "I just didn't have the answers"	1.1 Emotional reaction to ARMS	7
	1.2 Feeling powerless	7
	1.3 Putting on a 'brave face'	7
2. Getting Support: "I felt like I had a bit of a safety net"	2.1 "the help was there, a huge weight was lifted"	7
	2.2 Opening up in the presence of professionals	6
3. Moving Forward: "you just have to take each step as it comes"	3.1 What does the future hold?	6
	3.2 "learning curve"	6
	3.3 "good days and bad days"	5

Superordinate theme 1 – Initial Uncertainty: "I just didn't have the answers"

This superordinate theme is comprised of three subordinate themes representing the initial reactions and feelings of parents, which were associated with learning that their child was at risk of developing psychosis. Overall, it encompasses uncertainty about what ARMS means and about how to help their child. Parents appeared to believe there was a correct answer that professionals could provide.

1.1 Emotional reaction to ARMS

Across all participant interviews, a key aspect of the sense-making process appeared to be the initial reaction of parents to learning that their child might be at risk of psychosis. Parents described experiencing a range of thoughts and emotions when learning about ARMS, but the initial reaction appeared to be unanimous. All parents described

experiencing shock and surprise when the possibility of psychosis or hearing voices was mentioned:

"...you just feel numb and shocked and you don't know what to say, you don't know what to do and things like that 'cause[sic] you don't ever imagine that your child will suffer with things like that"
(Karen)

This indicated that the feeling of shock was the result of how ARMS deviated from the expectations parents had for their child's future. Karen refers to her child's experience of ARMS as 'things like that' indicating that it is too difficult for her to say. This may be further illustrated by her description of feeling 'numb', which was interpreted as an absence of feeling representative of her uncertainty and confusion.

Following the initial, shared reaction of parents, there were then differences in their response to ARMS. Several parents reported that learning that there was a risk of psychosis provided an explanation for the changes observed in their child. Three parents (Julie, Debbie and Carol) described a long process of seeking an explanation and were relieved that their concerns had been acknowledged and understood by others:

"...it gave me some sort of answer... it was good, in some respect, to have an explanation"
(Debbie)

In this segment, the use of 'in some respect' appears to illustrate the 'bitter-sweet' nature of ARMS. It appears to elude to an unspoken, 'bad' aspect of the explanation provided. Furthermore, 'some sort of answer' appears to suggest that it was potentially not the preferred explanation.

For some, there was a more positive, optimistic reaction to ARMS. Jonathan had understood the 'at risk' element to mean that there was something that could be done to prevent his daughter experiencing psychosis:

> *"they said there was a potential she could have a psychotic episode, which, sort of, to me said that as long as we are trying to manage it, we can try to prevent that… because it felt like there was a process underway to control it… … it felt more manageable as a situation" (Jonathan)*

In this description it is as though ARMS is something difficult to manage that needs to be controlled. However, the use of 'we' appears to suggest it is seen as something they can tackle as a family.

However, other parents experienced more negative reactions to ARMS. Several parents used the adjective 'scary' to describe how they felt about the risk of psychosis indicating that they were afraid of their child's experiences. Some parents also appeared to have questions about what psychosis was:

> *"I think more with psychosis you're going down more the line where she could just go down the street and attack somebody… I think when people are psychosis[sic] it's like, it's like… is it like a split personality, like they do it but they don't know they've done it?"*
> *(Julie)*

In this example, the fear experienced by Julie appeared to be associated with a belief that people experiencing psychosis are dangerous, or to be avoided. This appears to illustrate a shift in the usual parent-child relationship from the parent holding the power, to one where they are intimidated by and cautious of their child.

In addition, learning that there was a risk of psychosis appeared to make some parents doubt how well they knew their child and what they were capable of:

"I know he wouldn't hurt me or his little brother, but it was that word "psycho",
"psychosis" that made me think, 'maybe just watch out'"
(Joanne)

ARMS appears to act like an eclipse in the sense that their child is still present and the same person they have always known, but initially learning that there was a risk of psychosis appeared to obscure this from view and display something darker and more ominous to parents.

Another reaction of parents when learning of ARMS was to allocate blame. Some parents allocated blame to professionals for providing incorrect diagnoses:

"[The Psychiatrist] said she was doing it all for attention and what have you, and I wasn't happy with that. So I said that I wanted a second opinion… we got to see another psychiatrist."
(Carol)

Others held beliefs that they had somehow contributed to their child's experiences:

"…even to yourself you think, "Have I done something wrong?" "Have I done something to do this?""
(Julie)

"I felt like I've, I've caused this. This is my fault. And that was horrible"
(Charlotte)

1.2 Feeling powerless

Once participants had been told that their child met the ARMS criteria, they described not understanding what it meant and not knowing how to proceed. One parent described this as feeling 'powerless'. Several parents described scenarios they had experienced with their child, which they felt unequipped to manage. Parents had a desire to help and

protect their child but felt that they lacked the necessary skills to do so. This idea of lacking skills and not being trained to help their child was frequently discussed. In feeling 'powerless', parents appeared to perceive services as being 'powerful' and that there was a 'right' way to manage different situations which they did not understand:

"I felt a bit powerless, like to help her, because as a parent you want to sort of fix it and it's not something I necessarily had the skills to do… I'm not qualified or trained to do that sort of work"
(Jonathan)

"I wasn't trained to deal with her"
(Julie)

Upon learning about ARMS or that their child was hearing things other people could not, parents appeared to feel disempowered and unable to care for their child. This illustrates the pressure parents felt to seek someone 'qualified or trained'. Charlotte described losing confidence in her ability to parent and began to change how she responded to her daughter:

"I became very sensitive to [daughter] in the sense that I didn't know how to deal with the simplest of things with her… I didn't want to cause any possible harm"
(Charlotte)

This demonstrates a shift from the usual assumption that children are safest with their parents, to one where parents are frightened that they will 'harm' their child in some way. This appeared to be a product of the fear that parents held about their child's safety. Several parents in the study explained that their child had self-harmed or in some cases had attempted to take their own life. Consequently, parents worried about leaving their child, which had an impact on their social and work life:

"You just worry, worry all the time. You go to work, I'm thinking, when I come home I'm thinking has he done owt [sic] upstairs and that. It's hard.

It's really, really hard."

(Karen)

"...deep down I would think "what if we go home and she's dead, she's decided it's her time"

(Julie)

These extracts illustrate that the powerlessness and worry felt by parents was constant across all areas of their lives. It demonstrates the unwavering fear held by parents that their child could harm themselves and they would not know how to prevent it.

The powerlessness experienced by parents also appeared to be exacerbated by difficulty in finding an appropriate service. Three participants described being turned away by counsellors immediately after their child disclosed hearing voices:

"I always remember us seeing someone and they was[sic] like 'we just don't know what to do with her' and it was like… 'you're a professional. You know. We've come to see you and you're telling me that you don't know what to do with her?'"

(Julie)

In this segment, Julie's frustration is poignantly described when she is let down by the counsellor after she believed she had found someone to support her child. This appeared to spark further fear in parents as the person they perceived to have the answers, also felt unable to support their child.

1.3 Putting on a 'brave face'

Despite feeling powerless and uncertain about the meaning of ARMS, parents felt a responsibility to put on a 'brave face' for their child:

"But you have to put a brave face on. I don't like him to see me cry. It's very rare I cry in front of him."

(Karen)

This demonstrates the pressure parents felt to be perceived as able to cope and to hide their concerns. It is as though their 'brave face' is a mask they wear for the world to disguise their distress that they feel unable to remove. As discussed, parents began to perceive themselves to be 'powerless' in their parenting role and perceived services to hold the power. However, in their relationship with their child, parents felt compelled to remain in the more powerful 'parent role':

"I had to say to her "you don't have to, I'm the mum, I'm the adult, you're, you're a child… you don't have to worry about these things, it's my job to do that" and trying to take that responsibility away from her was really hard."

(Debbie)

However, often this meant that parents were trying to provide reassurance to their child when they were also worried and uncertain about the future, suggesting an internal struggle parents faced. For example, Joanne described being so worried about what would happen to her child that she was unable to sleep, yet when her son expressed worries about what was going to happen, she instinctively tried to reassure him:

"I said "It'll be fine, it'll be fine, you're young, you're young, you know, we'll figure it out, don't worry. We'll go see somebody".

(Joanne)

Joanne's repetition in this example feels as though she is reassuring not just her child, but herself as well. A further example of parents putting on a 'brave face' was in their approach to seeking help from services. Despite feeling that they were not 'trained' to help their child, several parents prioritised taking a proactive stance when attempting to elicit support. This was often accompanied by a sense of accomplishment for parents:

"...we were quite proactive in sort of getting the help and pushing it further" (Jonathan)

"I couldn't just sit on the side-lines without doing anything. So, she's got all the support she needs"
(Carol)

In using the term 'side-lines', Carol appears to compare the journey of seeking support to a sport and illustrates her desire in this comparison to be an active member of the team rather than a substitute on the side-lines. For those who had been less proactive in eliciting support from services, this was often described with a sense of regret:

"I think, going back in time, I wish I'd have done things differently myself and maybe fought a bit more to get her help sooner… I wish I could have talked to somebody at school and explained her symptoms or maybe if I'd have got her help earlier to deal with whatever it was it wouldn't have got to the stage it did"
(Debbie)

This segment is also reflective of the amount of guilt experienced by parents and the blame they placed on themselves for their child meeting the ARMS criteria. Interestingly, in using the word 'fought', Debbie also appears to compare the process of seeking support to a sport, specifically a fight, implying that services were the enemy.

'I just didn't have the answers' describes the early stage of making sense of ARMS and the process of trying to find answers. It discusses the initial shock, the accompanying feelings of self-doubt and uncertainty and ultimately, the brave persona parents felt they had to display despite these concerns. For many, the answers were perceived to come from professionals and others that had appropriate training. It also describes the stigmatising beliefs internalised by parents and their awareness of the stigmatising beliefs of others.

Superordinate theme 2 - Getting Support: "I felt like I had a bit of a safety net"

Parents turned to services for guidance as they felt they lacked the skills that were required to support their child. This theme encompasses parents' experiences of service involvement and accessing support.

2.1 "the help was there, a huge weight was lifted"

The above quote was used because it captured the immense strain and pressure parents felt prior to receiving support. The pressure was likened to carrying a 'huge weight' and the subsequent feeling of relief of the weight being lifted when services became involved in the care of their child, specifically when parents felt that there was a shared responsibility for their child's welfare:

> *"...even if she comes to us and we can't deal with it, we know that we can make a call and someone else can, not deal with it, but someone else can intervene and help us going forward."*
> *(Charlotte)*

Several parents discussed how limited their communication had become with their child which had increased the amount of pressure they were under and the size of the 'weight' they were carrying. Parents were consequently comforted by the prospect of their child having someone to confide in:

> *"I think that helped as well, just knowing that she had someone to turn to, someone to talk to."*
> *(Julie)*

However, several parents reported relying on services. Some parents suggested that they would not be able to cope without services. For some parents this created distress, as they were apprehensive about what would happen when services withdrew:

"I can't cope on my own, you know, so that's where I need someone else who is
trained who can help her"
(Julie)

In this segment, Julie poignantly describes her fears of how she would cope without services. This indicates the negative way in which parents appraise their own ability and again illustrates the perception of services as holding all the power to help their child.

2.2 Opening up in the presence of professionals

The experience of 'opening up' was described by the majority of parents. This included their own experiences, their observations of their child and also barriers that that made opening up difficult. FI were first suggested to participants, they all reported being willing to be involved. For several parents, prior to entering EIS, their child had been seeing other professionals. They described feeling '*out of the loop'* (Charlotte) which appears to elude to an inner circle, of which parents do not feel part and in which their opinion is not valued. For these parents, the option to be involved was something that they had been requesting so was readily accepted.

"Through the whole process we never knew there was a situation where you
could all sit down and talk about things. So as soon as we heard there was
potential to have family therapy… that's what we wanted."
(Jonathan)

The use of 'as soon as we heard' illustrates Jonathan's enthusiasm for attending which appears to demonstrate his frustrations with feeling 'out of the loop' and his desire to play an active role in his child's care.

Some felt that FI provided them with reassurance. Since parents doubted their parenting ability and felt uncertain about how to approach different situations, some benefitted greatly from being provided with some reassurance:

*"It's just like me getting my reassurance off them. Not that I'm a bad parent or
that I'm doing anything wrong because there was never no [sic] wrong answer."*
(Julie)

This also appeared to suggest that Julie had moved away from searching for answers
and instead seemed more accepting of the fact that there may not be a 'correct' answer
to find.

Additionally, parents benefitted personally from attending FI. For some, FI was viewed
as an opportunity for parents to be open and to receive support:

*"...when I had family therapy it was like, it was like my safe haven as well
because not only was [sic] they there for [daughter] they was [sic] there for me
as well... I need the support as well, you know. Whatever she's feeling
I feel it too."*
(Julie)

Julie's description of FI being a 'safe haven' illustrates how significant having
somewhere she felt able to share her concerns was to her. Her use of 'haven' conjures
images of an oasis and demonstrates how unique and special it was to her to have a
place where she felt supported. She also poignantly describes how she needed support at
the time and how FI was able to provide that to her.

Parents also reflected on how FI helped them to realise how closed and private they had
previously been:

"...we've all been our own little closed books and now we're not."
(Charlotte)

In this extract Charlotte describes the process of opening up very literally by comparing
herself and her family to being 'closed books' prior to involvement in FI.

Attending FI appeared to enable this communication between family members in an environment where they were able to share their opinions without them being misunderstood and without their openness leading to conflict:

"I suppose for me and [husband] it was more helpful definitely, you know I felt like I could say a few things in a safe place without [daughter] getting angry with me and them explaining to her what I meant"
(Debbie)

However, not all parents had a positive experience of FI. Some parents did not perceive it to be beneficial for their family. One parent reflected that her child may have engaged more readily with FI if the team taken more time to get to know her so that she was more familiar with them.

"I do think, personally, that if maybe they had just sat with her first and maybe just made her feel comfortable maybe it would have been more helpful for her. But at the time they just came and talked to us all together and I think that made her feel uncomfortable"
(Debbie)

Another parent had felt unable to open up for fear of upsetting her child. She believed that the process would have been more beneficial if both parties were spoken to separately initially.

"you felt as though you wanted to say things but you held back and in that situation where you've got the four people and you're conscious of the two that are asking the questions, but you're also conscious of the two that are just watching"
(Carol)

In this second stage of sense-making experienced by parents, they appear to be re-evaluating their beliefs about ARMS. It summarises the reactions of parents when services became involved with their family as well as their family's experience of

opening up whilst in the presence of professionals. Parents were relieved when receiving support from services as they were being involved in the process and felt that responsibility was shared. Experience of opening up varied for parents with some finding it to be a valuable experience and others finding it to be uncomfortable.

Superordinate theme 3 - Moving Forward: "you just have to take each step as it comes"

The final superordinate theme represents reflection. It illustrates how parents evaluated their situation and their expectations of the future. It describes a stage of adjustment where parents have developed more skills and strategies to help their child. This theme discusses the impact this has on the sense-making process whilst recognising that sense-making is ongoing.

3.1 What does the future hold?

Once parents had adjusted to the initial shock of learning that their child was at risk of psychosis, the matter of their child's future was frequently considered. All parents in the study expressed concerns about the impact that psychosis might have on their child's future. However, parents who had come to the end of their involvement with services (Julie and Debbie) or who were close to completing their work with services (Jonathan and Charlotte) acknowledged that their concerns about the future had reduced:

> *"I'm not as concerned about her as I was 7 or 8 months ago. It's not a worry that I have because I know that if she's feeling down, whether she speaks to me or her mum, she knows how to deal with it herself or she's got places to go. I know she's got a support network."*
>
> *(Jonathan)*

For others who were at a different stage in their treatment journey, these concerns remained. Parents held concerns about whether they would be able to *"lead a normal*

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life" (Julie) and whether they would be able to get a job. Equally, parents were concerned about how their child would cope away from home. Carol expressed worries about her daughter beginning university in September and similarly, Karen described a conversation she had with her son after he told her he would like to move out of the family home:

> *"Well eventually I hope that he does. I know that he wants to, but he can't. He knows that he can't yet. He's not ready yet."*
> *(Karen)*

This illustrates how conflicted Karen felt. She wanted him to be able to live independently at some point but also described feeling frightened of what might happen if he was on his own. Karen later went on to mention that one of the reasons he could not move out is because she could not drive and it would be difficult for her to get to him. In this case, it appeared that Karen's concerns about her son moving out were reinforced by her concerns that she would be less available to help him. Although her focus was on her son not being 'ready yet', there was also an implication that she was also not ready for him to leave home.

When talking of the future, some parents expressed sadness about how ARMS had altered the trajectory of their child's future. Parents discussed how their child had needed to miss several days of school, for instance, but also more considerable impacts of ARMS. Julie explained that her daughter was unable to apply to be a nurse due to being on medication:

> *"She was a bit upset the other week cause she was gonna [sic] apply for the army, to be a nurse in the army and straight away they've said no because she's on medication ... she thinks that if she's on the medication that this is gonna [sic] stop her from doing things in life."*
> *(Julie)*

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In this example, it is as though that ARMS symbolises a barrier that appears between their child and their desired future. Some parents also appeared to go through a process of adjusting to the loss of the imagined future they had for their child:

> *"You never expect your, your child to, to end up like that. Not when you know how much potential they've got and what a nice person that they are. That hurts you more, do you know? And he's had a go like for uni and that, he'd be…this year he'd have been graduating."*
> *(Karen)*

In this segment, it appears that reflecting on how the future could have looked had things been different was a difficult process for Karen. It is as though ARMS is perceived as something that has stolen the future that could have been and that she believed her child was capable of.

3.2 "learning curve"

In the initial stages of learning about ARMS, parents felt that they lacked knowledge and wanted to learn skills that could help their child. This subordinate theme discusses parents' appraisals now that they have been involved with services and have gained knowledge about ARMS. One parent described a "*learning curve" (Julie)* which appears to summarise the general experience.

Parents frequently discussed feeling that they had gained knowledge. They described feeling that they had a better understanding of their child and of their reasons for their behaviour. One of the main issues initially experienced by parents was frustration that their child was not communicating their feelings and experiences. Debbie described how throughout the process she had gained an understanding about why this was:

> *"…she was scared to talk because the voices were telling her things, you know, so she wouldn't talk and I understand that now and me pushing her probably*

The use of 'I understand now' appears to symbolise a move towards gaining confidence, where she now feels better equipped to help her child than she felt previously. Parents felt more equipped to cope with different situations. They described developing skills and an ability to recognise when their child did not feel like talking. Julie explained that she *"can see signs now" (Julie)* of when her daughter is struggling, where her experiences had previously appeared to come without warning. Similarly, since they began working with services, Karen felt able to make suggestions to her son about strategies he could try when he was low in mood. She described a situation where he had been struggling and she was able to say *"do your deep breathing, or go and focus on something" (Karen)* which had ultimately helped her son to feel better. This appears to demonstrate a change in the relational dynamics between parents and services to one in which there is a greater balance of power, and in which parents felt as though they had more autonomy.

Throughout the therapeutic process, parents noticed that communication had improved within the family. During interviews, they reflected that they had spent little time talking prior to their involvement with services and recognised that this had improved:

> *"She'll just have conversations now … just general conversation which actually when I think about it we weren't really doing"*
>
> *(Jonathan)*

It is as though the process has allowed time to reflect and helped to shed light on areas that parents may not have considered. Several parents recognised that they had been expecting open communication from their children but had struggled with this themselves. Charlotte noticed that she had been hiding her feelings from her children and recognised the impact this was having on their relationships:

"I think I speak more openly with the children about what I'm feeling… I think maybe prior to all this I'd have just probably snapped at them and then apologised afterwards but now I think I probably wouldn't even snap at them I'd just go "right, I'm not having a very good day today" and I think (pause), not that I'm putting on my children, but I just feel that we can be that way with each other, and it's nice!"
(Charlotte)

Improving communication between parents and their children positively influenced several areas of their lives. One of the most frequently reported by parents was how it had made their family closer:

"…as a family we're a lot closer and she just talks so much more to us now so. Yeah I mean something must have come from that for her as well because she's so much more open"
(Debbie)

Additionally, the learning curve also encompassed parents' reflections about things they could have done differently. Debbie, who had stopped FI after three sessions, reflected that had they continued for longer *"it might have got easier" (Debbie).*

3.3 *" good days and bad days"*

Recognising that there are going to be *"ups and downs" (Karen)* appeared to be an understanding shared by several parents. Initially parents described concerns about the future and what their child's life might be like if they were to go on to experience FEP. As parents developed a better understanding of their child's experiences and gained confidence in managing different situations, they were able to gain a more balanced view of the future. This contrasts with the initial emotional response of parents, as it includes the recognition that there will still be good days, which indicates a level of optimism about the future. This idea was more frequently discussed by parents who were further into treatment, or who had been discharged from services. Jonathan

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explained that his daughter will *"have good and bad days"* and felt accepting of this. He believed that he had a better understanding of how to talk to her and was aware of the available support appeared to contribute to this.

> *"But yeah good days and bad days. The good days are outweighing the bad days at the moment."*
> *(Carol)*

For others, this represented the unpredictable element of their situation. Karen explained that her son would have several successive 'good days', which would make her feel that things were getting better, then there would be a 'bad day' which made her worry about her son and concerned that all progress up to that point had been lost:

> *"...we was [sic] in a positive place but then it goes straight back down again when he has his off days"*
> *(Karen)*

This illustrates two opposing positions of parents, which were indicative of their stage in the therapeutic process. As parents developed more confidence and acquired knowledge, they were able to recognise that there would be 'bad days' without the fear that it indicated regression.

'Moving forward' summarises the final stage of sense-making described by parents. It encompassed parents' predictions of the future and how these had changed over time. It also includes the reflections from parents about changes they have observed within the family and in their own confidence. There also appeared to be recognition from parents that the process of making sense of ARMS would be ongoing.

Discussion
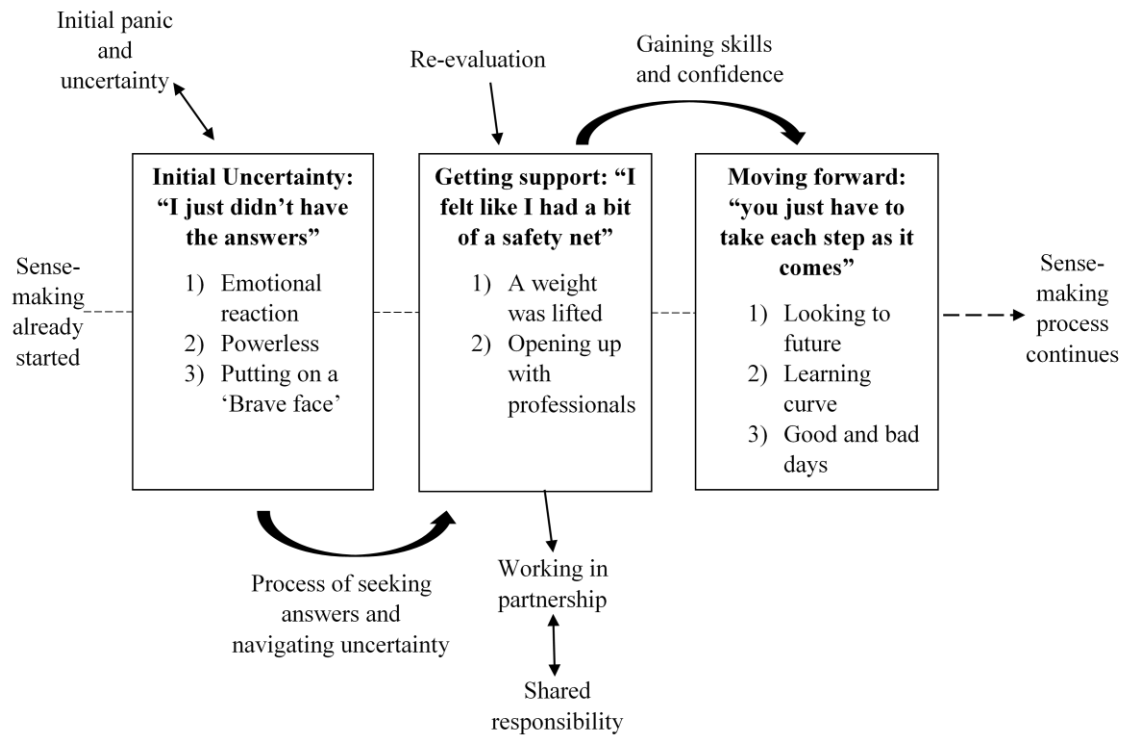
Figure 2. A diagrammatic representation of identified themes.

The findings of this study provide an insight into the process experienced by parents

trying to make sense of ARMS and are displayed diagrammatically in Figure 3. All

parents reported a similar experience of sense-making and appeared to progress through

similar stages. This is consistent with literature describing sense-making as a central

human process (Weick, Sutcliffe & Obstfeld, 2005). The first stage described by parents

illustrates the initial fear and uncertainty experienced when learning about ARMS. This

mirrored the initial 'startling phase' proposed by Romme and Escher (1989). The

'startling phase' describes the initial shock and anxiety experienced by those hearing

voices. Although voice hearing is just one possible unshared experience of those

meeting the ARMS criteria, this suggests that the initial reaction of parents mirrors that

of their children, even when their child has not experienced a FEP. These findings were

in accordance with those of parents making sense of alternative diagnoses, who also reported an emotional reaction to the diagnosis that was characterised by shock (Harborne, Wolpert & Clare, 2004; Levi, Marsick, Drotar & Kodish, 2000).

The results also demonstrated a power dynamic between parents and professionals. During the initial stages of learning about ARMS and trying to find appropriate help, parents felt unskilled and lacking in the necessary training to help their child. This affected their confidence in their ability to support their child. Parents looked to services as having the necessary skills and as being able to provide the 'correct' help for their child. This reinforced the powerlessness experienced by parents, as they perceived providing care as a role that they should fulfil. Parents are also under considerable pressure to meet societal expectations of the 'perfect parents' (Douglas & Michaels, 2005; Henderson, Harmon & Newman, 2016; Lee, Schoppe-Sullivan & Dush, 2012). These societal-oriented pressures of perfection were linked with poorer adjustment in parents (Lee, Schoppe-Sullivan & Dush, 2012). There also appeared to be evidence of professionals reinforcing this power dynamic. This is consistent with literature discussing colonialism in therapy, which suggests that psychological intervention takes away an individual's natural resources and diminishes their confidence in their own resources (Rober & Seltzer, 2010). Furthermore, there is an argument that psychology has played a role in professionalising distress and consequently sustaining the need for the profession (Dineen, 1998). This demonstrates the importance of reflection in the profession and a move away from the 'expert' position. In contrast, parents had experience of being turned away by counsellors when their child disclosed hearing voices, as they could not provide support for psychosis. This corresponds with literature suggesting that other staff working with mental health can often be unwilling, or unable to directly address experiences associated with psychosis, such as voice hearing, due to feeling limited in what they are able to offer service users (Coffey & Hewitt, 2008).

Mental health professionals have also reported feeling powerless to help reduce the distress of service users with unshared experiences (McMullan, Gupta & Collins, 2018). This highlights the need to offer further training and support to staff to help them feel more equipped to normalise and understand voice hearing and other unshared experiences.

The second stage described by parents described their experience of receiving help from mental health services and of opening up in the presence of professionals. The experiences of FI reported by parents in the current study mirrored those of parents attending family interventions for first-episode psychosis (Nilsen, Frich, Friis, Norheim & Røssberg, 2016). Parents in the Nilsen and colleagues (2016) study also reported an improvement in communication within the family, as well as the development of an understanding of what psychosis meant for their child and an acceptance of this. This included an acceptance that the path to recovery may be challenging. This demonstrates that the parents included in this study appeared to find the same aspects of FI useful despite differences in their child's presentation.

The findings also suggested variation between the expectations of parents compared to professionals. The initial stage of sense-making described the uncertainty experienced by parents and their desire to gain skills and understanding. Participants discussed wanting answers, seeking a diagnosis and believing that professionals would provide an explanation for what was happening to their child. Open Dialogue, an approach that focuses on the importance of language and consistency in mental health care, describes the ability to tolerate this uncertainty as a key component of working with families experiencing psychosis (Seikkula, Alakare & Aaltonen, 2001). Rather than providing certainty, Open Dialogue advocates a collaboration between services and families to co-construct a meaning of their child's experiences that makes sense to them (Lakeman,

2014; Seikkula, Alakare & Aaltonen, 2011). It encourages using the resources the family already have (e.g. knowledge) rather than replacing them with professional resources, which could perpetuate feelings of powerlessness. This challenges the traditional view of professionals as 'experts' and empowers families by helping them to make sense of their experiences in a way that fits with their beliefs and understanding. Further research could explore the benefits of incorporating aspects of Open Dialogue into FI for ARMS.

However, whilst an important aspect of FI is focusing on the experience of the individual rather than viewing them in the context of a diagnosis, there is potentially more information that parents require. During interviews, some parents held negative beliefs about psychosis that were informed by stigma and others asked the researcher questions about what psychosis was. Firstly, this demonstrates that parents either hold or are aware of stigmatising beliefs about psychosis, which is consistent with other literature (Struening et al, 2001). Secondly, it illustrates that being involved in an EIS for a number of months did not always help to diminish their stigma about psychosis. Stigma is influenced by a number of factors including interactions with services, the information provided by the media and the beliefs of those in the local community (Angermeyer, Schulze & Dietrich, 2003; Buizza et al, 2007). Although interactions with services are not the only way to reduce stigma held by the public, it might be assumed that contact with EIS would result in less stigmatising attitudes towards psychosis. This suggests that as well as considering a person-centred understanding, services could potentially do more to normalise parents' experience as this has been shown to help service users feel more comfortable, validated and trusting of clinicians (Lüllmann & Lincoln, 2013).

The final theme of sense-making identified by parents in this study, discussed the process of moving forward. The majority of parents reported having gained knowledge and confidence in how to best support their child. The stage of treatment that the family were in also influenced how they perceived the future. Several parents acknowledged that the future would hold good days and bad days, recognising that recovery would not be a linear process, and is unique to each person. This mirrors literature describing personal recovery (Slade, 2009; Turner-Crowson & Wallcraft, 2002; Davidson, 2005). In this case, 'recovery' does not refer to the absence of symptoms or suffering, but rather focuses on the development of resilience and skills that can help provide a person with a sense of control over their situation (Davidson, 2005; Jacob, 2015). Additionally, despite initially looking to professionals to gain knowledge, parents reported that the knowledge they had gained in this third stage of sense-making had generally come from the process of opening up as a family. This is also consistent with the dialogism aspect of Open Dialogue, in which the active process of listening and responding creates a shared language and new meanings for experiences (Seikkula, Alakare & Aaltonen, 2011).

Another key finding from the study was that some parents felt that there was not sufficient support available for them throughout the treatment process. Others reflected that they had needed more help from services than they felt able to ask for. Current guidance from the Care Act 2014 states that all carers are entitled to a carer's assessment, which aims to identify any areas of support a carer might need. This highlights a potential problem with carer's assessments as the results have demonstrated that parents felt pressure to 'put on a brave face' and hide their concerns. Additionally, some parents felt under scrutiny by services after being invited to attend FI, suggesting that parents may not always communicate to others that they need support. This creates an internal conflict for parents: either acknowledge that they feel unable to do their 'job'

as a parent and consequently feel deskilled; or keep their concerns to themselves. This is something that staff need to be aware of moving forward, by acknowledging this conflict and acknowledging that seeking help is difficult. Furthermore, two parents suggested that they could have benefitted from individual sessions alongside family work as, for the same reasons, they did not always feel comfortable sharing their concerns in front of their child. Further research could explore the outcome of offering individual support to parents and whether this could be incorporated into the delivery of FI.

Limitations

Whilst within the recommended sample for an IPA study, the findings represent the voices of a small population of White-British, parents from EIS in an attempt to recruit a relatively homogeneous sample. However, only one of the seven participants was male. There were some differences in the experiences reported by participants, however these differences were not attributable to gender, but rather differences in family dynamics which, for example, had an influence on how they engaged with FI. So despite the underrepresentation of males within the study, no gender differences were identified when comparing the interviews. Recruitment utilised purposive sampling and participants voluntarily gave up their time, which may suggest that they were more likely to be parents who were able to open up about their experience, which may influence the generalisability of the findings. Within the sample included, none of the families interviewed had experienced their family member being diagnosed with a FEP. This also may have affected the experiences of the parents included and consequently the findings will not be reflective of the journey of all parents. Furthermore, for this group of people, FI appears to have played a role in the process of making sense of their experience of ARMS. However, these findings cannot conclusively suggest that FI was

the mediator of this process. Further research could explore this further by comparing other types of support available to parents to see if similar results are achieved. Equally, as this study was cross-sectional in design, further research could provide more information into the sense-making process over time.

Implications

This is the first study to explore how parents experience FI for ARMS so it could provide key information into how FI could be adapted to better suit ARMS individuals and their families. Parents described some barriers to FI that may be useful in helping to engage others in the future, such as introducing members of the FI team to service users prior to beginning FI so that they can become more comfortable with the team. Gathering further information of this nature from parents could lead to better outcomes for families.

The findings of this study also reinforce the need to provide support for parents of people who have been identified as meeting the ARMS criteria. The high levels of burden and distress experienced by those in caregiving roles has been well documented and the findings of this research demonstrate that it is equally present for the parents of those at risk of psychosis (Addington, Coldham, Jones, Jo & Addington, 2003; Fernando, Deane, McLeod & Davis, 2017). Furthermore, a wealth of evidence has demonstrated the links between parental wellbeing and the outcomes of their child (O'Brien et al, 2006; Pharoah, Mari, Rathbone & Wong, 2010; Reus et al, 2016)

Conclusions

Overall, the findings of this study have provided an understanding of how parents make sense of ARMS. These findings demonstrate that the most valuable aspect of the treatment journey was being involved in the process of supporting their child. This appeared to play a significant role in building the confidence of parents. Furthermore, the results reinforce the importance of offering support to parents of at-risk individuals and highlight that parents are not always comfortable asking for help.

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Part Three: Appendices

Appendix A: Reflective Statement

Writing a thesis was something I was incredibly apprehensive about and this fear has recurred at several points throughout this process. Sitting in front of a Word document creatively titled 'Thesis' has, on several occasions, led to experiences of 'imposter syndrome' where I would have moments of disbelief that I had found myself in this situation. I put this down partly to previous assumptions about a thesis being a ten thousand word doorstop (which, understandably, is quite an intimidating prospect) and partly to a genuine concern that this would just be something I would be unable to do, because it would not be good enough.

The thing I have found most difficult during this process has been being aware of the vast amount of work it entailed. On occasions, this was overwhelming and made it difficult to know where to start. There have been several points where I have just stared at the task in front of me with no idea of how to begin. I expressed these concerns to my supervisors who suggested breaking it down into stages and making sure to celebrate after each one and that is what I did. The main lesson I have taken away from this process is that the best thing to do is just start and take it step by step.

Development of the idea

Not long after starting the doctorate, I was introduced to the psychosis continuum during a lecture (Os, Linscott, Myin-Germeys, Delespaul & Krabbendam, 2009). This discussed how the interpretation of a belief is dependent on several contextual factors and that a belief perceived to be 'unusual' in one context may not be in another. It also implies that the unshared experiences of those with a diagnosis of psychosis are also present in people who may never present to services.

During this lecture, one of my now supervisors mentioned that those with religious beliefs could also be on this continuum as they hold beliefs that could be classed as unusual and that are not universally shared. Having been raised in the Roman Catholic faith and having attended a Roman Catholic school, this was an eye-opening comparison. The beliefs that I had been brought up with were on the same spectrum of unshared beliefs as those with diagnosis of psychosis. I had never before heard this critical perspective and it made me realise that I had blindly accepted that psychosis existed without challenge. When attending the research fair I was consequently drawn to completing a project in this area. During a meeting with my supervisors, the concept of the At Risk Mental State (ARMS) criteria and its role in identifying those at risk of psychosis was discussed. This was something I was fundamentally drawn to. On the one hand, the concept of early intervention was something I had always believed to be incredibly important, yet on the other hand, I had this new found critical perspective on what constituted the unshared experiences and beliefs that resulted in a diagnosis. After becoming aware of the current debate about the utility of the ARMS criteria, I wondered how this must feel for those meeting it.

Being from a close family, I have always found myself drawn to a systemic approach to working with service users. Whilst I have seen first-hand the benefits that a one-to-one approach can have with service users, I have always held the perspective that an individual's context plays a vital role in their experiences. Consequently, it made sense to me to consider how this was understood as a family and with some tweaking and discussion, the idea was born.

Conducting the Research

<u>Empirical</u>

Using qualitative research for the first time presented challenges. I found that I had placed a great deal of pressure on myself 'to do it right'. Before my first interview, I read everything I could find that discussed how to conduct a 'good' semi-structured interview, as I was apprehensive that I would be unable to elicit sufficient depth. I was also conscious of the impact of my own values and beliefs. After completing a reflexive interview with my supervisors, I was able to reflect on, and become more aware of, my own assumptions. This was a useful exercise but in some ways made me more self-conscious during interviews.

This concern about 'not being good enough' also fed into data analysis. Data analysis was an aspect of the process I had been apprehensive about from the beginning. Initially I was afraid that I would not be able to go into enough depth and that there would not be enough to talk about. However, this fear was quickly discounted with the more interviews I completed. I found my interviews to be incredibly interesting and was lucky enough to have participants who were eloquent in communicating their experiences, journeys and reflections with me. However, when I printed off my transcripts, the fear returned. I felt incredibly overwhelmed and immobilised. Despite having already gone through them several times, I kept them in a folder that I carried in my bag everywhere I went for weeks. When on trains, waiting for meetings, or when I found myself with a spare moment, I would look through them and add to my notes. On reflection, whilst this enabled me to become familiar with the data I had collected, at the time it added to the gargantuan task that lay ahead of me. When looking at all of the notes that I had made and all of the quotes that I had highlighted, I had no idea how to condense this into something even remotely manageable. However, when I sat down

with some flash cards, initial codes and quotes, I found that the data appeared to fit together more easily than I had expected. There was still a considerable amount of time spent rearranging the cards and considering alternative ways that they fitted together, but compared to how arduous I had expected the process to be, it really felt like the themes I had identified made sense. When I explained my themes to my research supervisors, I was honestly surprised that the themes made sense to them, too. It felt like the findings revealed a real story, which provided me with another burst of energy and renewed interest in my research - a welcome addition to the process of writing up.

Systematic Literature Review

The systematic literature review (SLR) was always something I felt I had more control over. With the empirical paper, there were several occasions where the progression of the process was placed into the hands of someone else, such as waiting for ethical approval, and during recruitment. However, the completion of the SLR was ultimately down to my own motivation and on reflection, I am incredibly grateful I started early!

After my interest in my empirical paper was piqued, I became conscious of conversations and assumptions about psychosis. I started to notice the frequent, inappropriate use of the word 'psycho' in everyday conversations, in songs and in the media and it gave me a small insight into how it must feel for service users to have their experiences labelled as 'psychosis' when it has such negative connotations in our society. The idea of reviewing the factors that influenced how caregivers (as opposed to service users) experienced stigma was arrived at relatively quickly. I also found the content of the articles to be interesting, which aided the process. I definitely underestimated the amount of time that goes into conducting a SLR, but ultimately I felt like I was developing a much under-reported narrative by synthesising the available literature.

My Experience

Overall, I have found the process incredibly rewarding. As I head closer to submission I can't help but reflect on how far I have come and on how much work had to be done before I could even start to write the words on these pages. It has also challenged my views of research. Prior to this process, I viewed research as something that I would have to do and something that did not come naturally to me. However, despite being challenging, it is now something I hope to continue with in my career. Using IPA has played a considerable role in this shift as it allowed me to maintain the individual voices within the research, which I ultimately think has made the research more powerful. I have learned several things throughout this journey. First, to just keep going. When I felt overwhelmed by the many hurdles that lay ahead, I learnt to set small, achievable goals, which enabled me to tackle one hurdle at a time. Secondly, I have learned about my own views and assumptions, which I believe will be useful in the progression of my career and in future research. Finally, I have learnt that I can only do my best. The amount of time spent tangled in fears of not doing it right was counterproductive. Whilst my drive to do well has inevitably aided my academic career, you can never do more than your best and striving for a 'perfect' interview was unrealistic. In spite of my self-doubt and apprehensions, I did it, and I can't help but feel incredibly proud of what I have achieved.

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Appendix B: Epistemological Statement

The ontological beliefs and epistemological stance of a researcher undeniably underpin their approach to research and their interpretation of data. It is important for researchers to reflect on their position in order to ensure they are closely aligned to the selected methods (Bracken, 2010). This statement intends to clarify the stance adopted by the researcher and its influence on the development and completion of this thesis.

A positivist stance assumes that there is a truth that can be accessed by observation and experiments and generally underpins the majority of quantitative methodologies (Guba & Lincoln, 2005; Ryan, 2006). This stance was rejected for several reasons. Firstly, the assumption that there is a universal experience of parents is inconsistent with literature suggesting that each person experiences psychosis differently (McCarthy-Jones, Waegeli & Watkins, 2013). Secondly, the debate over whether the ARMS criteria is able to identify an at risk population did not appear to fit with a positivist stance. Finally, sense-making is considered to be a subjective process which may not always be explicitly measureable and consequently may not be discoverable through quantitative means (Davis, Nolen-Hoeksema & Larson, 1998).

In contrast to positivism, social constructionism argues that knowledge is constructed through language and social interaction, rather than there being an absolute truth (Burr, 2018). A social constructionist approach would understand reality as subjective and influenced by the experiences and context of an individual (Ormstrom, Spencer, Barnard & Snape, 2014). This has been a crucial aspect of this research as it is particularly relevant to the construction of psychosis in society. As discussed in the empirical paper, in Western society, a person with a diagnosis of psychosis is often assumed to be violent or dangerous (Link et al, 1999). However, in other cultures, the same experiences can be positively regarded and held in high esteem (McCarthy-Jones,

Waegeli & Watkins, 2013; Phillips III, Lukoff & Stone, 2009). This demonstrates the importance of context and social factors on how unshared beliefs or experiences are interpreted. With relation to the current study, it was recognised that each parent would have a different experience of sense-making as a result of their context and subjective experience. As a result, a qualitative methodology was selected in an attempt to capture the subjective experiences of participants more broadly.

Several qualitative methodologies were considered for the research. Grounded Theory was discounted as the research aimed to explore the experience of parents, rather than to develop a theory on the topic. Discourse Analysis was also considered due to its focus on the use of language throughout an interview. However, the aim to understand the lived experience of participants led to this approach being rejected as Interpretative Phenomenological Analysis (IPA) also considers the linguistic aspects of interviews, without being limited to them.

IPA was selected due to its focus on the subjective experience of each participant, with the intention of exploring how they made sense of their situation (Smith & Osborn, 2004). Furthermore, the 'interpretative' aspect of IPA discusses the principle of hermeneutics, a method of interpretation utilising written, verbal and non-verbal communication (Smith, Flowers & Larkin, 2009). It recognises the double hermeneutic position the researcher is placed in as they attempt to understand how participants understand the world. This acknowledges the significance of considering the lens of a researcher due to the impact it will inevitably have on the interpretation of the data. Consequently, this methodology was deemed to fit most appropriately with the aims of the research and the researcher's social constructionist stance.

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Appendix C: Submission guidelines for Clinical Psychology Review

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Author names and affiliations. Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author within the cover letter.

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A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

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Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

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List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

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Appendix D: NICE Qualitative Quality Checklist

Checklist

Study identification: Include author, title, reference, year of publication	
Guidance topic:	**Key research question/aim:**
Checklist completed by:	

Theoretical approach

1. Is a qualitative approach appropriate? For example: • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure	Comments:
2. Is the study clear in what it seeks to do? For example: • Is the purpose of the study discussed – aims/objectives/research question/s? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed	Comments:

Study design

3. How defensible/rigorous is the research design/methodology? For example: • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified?	Defensible Indefensible Not sure	Comments:

Data collection

4. How well was the data collection carried out? For example: • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/inadequately reported	Comments:

Trustworthiness

5. Is the role of the researcher clearly described? For example: • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described	Comments:
6. Is the context clearly described? For example: • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances • Was context bias considered	Clear Unclear Not sure	Comments:
7. Were the methods reliable? For example: • Was data collected by more than 1 method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to?	Reliable Unreliable Not sure	Comments:

Analysis

8. Is the data analysis sufficiently rigorous? For example: • Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results? • How systematic is the analysis, is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data?	Rigorous Not rigorous Not sure/not reported	Comments:
9. Is the data 'rich'? For example: • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well has the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites?	Rich Poor Not sure/not reported	Comments:
10. Is the analysis reliable? For example: • Did more than 1 researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data if possible and relevant? • Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported	Comments:
11. Are the findings convincing? For example: • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent?	Convincing Not convincing Not sure	Comments:

12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant	Comments:
13. Conclusions For example: • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this enhance understanding of the research topic? • Are the implications of the research clearly defined? **Is there adequate discussion of any limitations encountered?**	Adequate Inadequate Not sure	Comments:
Ethics		
14. How clear and coherent is the reporting of ethics? For example: • Have ethical issues been taken into consideration? • Are they adequately discussed e.g. do they address consent and anonymity? • Have the consequences of the research been considered i.e. raising expectations, changing behaviour? • Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported	Comments:
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + –	Comments:

Appendix E: NICE Quality Checklist ratings

Paper	Checklist Score Item														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Score
Koschorke, et al (2017)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+ +
Baron, Salvador & Loewy (2018)	Appropriate	Clear	Defensible	Not sure / Inadequately reported	Not described	Clear	Reliable	Rigorous	Not sure	Reliable	Convincing	Relevant	Adequate	Not reported	+ +
Krupchanka et al (2016)	Appropriate	Clear	Defensible	Appropriately	Not described	Not sure	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+ +
Wong, Kong, Tu & Frasso (2018)	Appropriate	Unclear	Defensible	Appropriately	Not described	Not sure	Reliable	Not Rigorous	Poor	Reliable	Convincing	Relevant	Adequate	Appropriate	+
McCann, Lubman & Clark (2011)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Poor	Reliable	Convincing	Relevant	Adequate	Appropriate	+ +
Wainwright, Glentworth, Haddock, Bentley & Lobban (2015)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+ +
Buizza et al (2007)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not reported	+ +

Paul & Nadkarni (2017)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Not sure	Convincing	Relevant	Adequate	Not reported	+ +
Poonnotok, Thampanichawat, Patoomwan, Sangon (2016)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	+ +
González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not reported	+ +
Schulze & Angermeyer (2003)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not reported	+ +
Angermeyer, Schulze & Dietrich (2003)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Not reported	+ +

Appendix F: Submission guidelines for The International Journal of Qualitative Studies on Health and Wellbeing

Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

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One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

2. Should contain a structured abstract of 200 words. A structured abstract should follow the structure: Purpose, Methods, Results, and Conclusions.

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5. Between 5 and 10 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

6. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
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This work was supported by the [Funding Agency] under Grant [number xxxx].
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This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

7. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.

8. **Biographical note.** Please supply a short biographical note for each author. This could be adapted from your departmental website or academic networking profile and should be relatively brief (e.g. no more than 200 words).

9. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.

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16. **Units.** Please use SI units (non-italicized).

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Appendix G: Participant Information Sheet

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Participant Information Sheet

Researcher: Georgia Parratt

Thank you for showing interest in this research project which is being conducted as part of a Clinical Psychology Doctorate at The University of Hull. Before you decide to participate, the following information is designed to ensure that you understand why the research is being done and what it will involve. Please read the information outlined below and feel free to ask questions if you would like to know more.

Research Title

"An IPA analysis of parents' experience of making sense of at risk mental state (ARMS) through family interventions"

What is the purpose of the research?

This research aims to find out about the experience that parents had of family interventions for individuals with at risk mental state. There is currently no information about how family members experience family interventions in these situations. Gaining an understanding of the experience of family members, more specifically parents, can help to develop the intervention to make it as beneficial as possible for future families in your position. As someone who has taken part in family interventions, hearing about your experience will provide valuable information about what it was like for you and the impact that it has had on you and your family.

Do I have to take part?

No. It is entirely up to you whether or not you agree to participate. If you do decide to take part in the study, you are still able to withdraw at any time up to the point of data analysis. You do not need to give any reason for withdrawal. If you decide not to participate it will not impact on any care you might be receiving.

What does it entail?

You will be asked to attend an interview at a time and place convenient to you. The interview will consist of some broad questions to guide the discussion about your experience of family interventions. All other participants will have been asked the same set of predefined questions but may be asked other questions that follow on from what is being

discussed. It is difficult to predict exactly how long the interview will last, but it will usually last approximately an hour. You will be given the opportunity to take a break or get a drink during the interview if you feel that you need to or leave completely at any time.

Will it be confidential?

All information collected during the study will be kept completely confidential. The interview will be recorded on an NHS encrypted laptop which means that the recording cannot be moved from the computer and none of your details will be associated with the recording. The recording will be destroyed following transcription of the session.

Once you consent to take part in the study you will be allocated a unique number which will be added to the consent form that you will complete. These forms will then be held separately from the information gathered from the interview by the Academic Supervisor in a locked cabinet at The University of Hull.

Points discussed, and potentially direct quotes from the session will be included in the write up of the research, however, all identifiable information will be removed. Anonymised data collected will be kept for 10 years on secure network drives at the University of Hull.

You are able to withdraw from the study up to the point of transcription. If you withdraw before this point the session recording would be destroyed and no information from the session would be used in the study.

What will happen to the results of the research?

You will be asked whether you would like to receive a summary of the study once it has been completed. If you agree a two-page summary of the research and the findings will be sent to you. You are also welcome to request a full copy of the research if you wish. You will also be invited to attend the Research Conference where the results of the project will be presented.

Who can access my data?

Data collected from the study will only be accessed by the Chief Investigator and the Academic Supervisors. The recordings of the interview will be stored on the encrypted laptop of the Chief Investigator which is not used by anyone else. Some of the things discussed in the interviews will be included in the write up of the study but anything included will be anonymised.

Who is sponsoring the study?

Humber NHS Foundation Trust and The University of Hull are the sponsors for this study based in the United Kingdom. We will be using information from you in order to undertake this study and we will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Hull

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will keep identifiable information about you for 10 years after the study has finished. You can find out more about how we use your information by contacting any of the contacts listed below.

Are there any risks?

It is difficult to predict how discussing experiences might affect you. Previous literature suggests that when someone is told that they are at risk of developing psychosis (or at risk mental state/ ARMS), it can have an effect on other members of the family. Discussing how family interventions was or is going for you may bring up how you feel about it. Therefore, if you have found it to be a stressful time for you, then it is possible that the interview may cause you distress when you are discussing it. You do not need to answer all of the questions if you do not wish, and you will not be pressured into discussing anything that you do not feel comfortable sharing. You will also be provided with a list of numbers that you can contact afterwards if you would like support.

Are there any benefits?

Sometimes people might find it useful to have an opportunity to discuss their experiences. Also, it is hoped that this work may have a positive impact in improving family interventions for future families in your position.

What if I have a complaint?

If you have any complaints about the project or any aspect of the process, several people you can contact are listed below. If you are unhappy with how your complaint has been handled, you can contact the Research Co-ordinator at the University of Hull (outlined below) who will help you to take your complaint further.

Ethics

This project has been ethically approved by the National Health Service (NHS) Ethics Committee.

Contacts

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Appendix H: Informed Consent Form

UNIVERSITY OF HULL   NHS Humber NHS Foundation Trust   Hull and East Yorkshire Hospitals NHS NHS Trust

<u>Informed Consent Form</u>

Research Title:

"An IPA analysis of parents' experience of making sense of ARMS through family interventions"

Name of Researcher: Georgia Parratt   Please initial boxes

1.	I confirm that I have read and understood the information sheet dated 10/04/2018 (Version 2.1) for the above study.	
2.	I have been given the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.	
3.	I understand that participation is voluntary and that I am free to withdraw at any time up to the point of data analysis and transcription. I understand that my decision to withdraw would not impact upon my care or legal rights.	
5.	I agree to take part in an interview and that this interview will be audio recorded.	
6.	I am aware that direct quotes from the interview may be used in the research and I understand that they will be anonymised.	
7.	I am aware that any comments that could incriminate myself, or others, would be acted upon and required to be disclosed to the relevant authorities.	

Name of participant   Date   Signature

_____   _____   _____

Name of person taking   Date   Signature
consent

_____   _____   _____

Date: 22/07/2018
Version Number: 3.1
IRAS ID: **242096**

Appendix I: Interview Schedule

Interview Schedule

1. Can you tell me what it was like finding out that your child met the At Risk Mental State (ARMS) criteria?
   Possible prompts: How did you feel? What did it change? How did you understand it? How was it explained to you?

2. How did you feel about family interventions (FI)
   Possible prompts: Did you have any hopes/fears about it? Did you have any expectations about what it would be like?

3. What made you agree to it?
   What was the process of deciding like?

4. What was your experience of coming together as a family?
   Possible prompts: What was it like for you? What have your experiences of coming together in the past been like, if you have had any? Was there anything that you heard that was different from what you had thought before?

5. How has FI affected your family?
   Possible prompts: Have you noticed much change? Have you noticed any changes in the way that you communicate with one another? Do you feel any different now than when you started?

Appendix J: Participant Support Sheet

Sources of support and information regarding psychosis and at risk mental state (ARMS)

The **Psychosis Service for Young People in Hull and East Riding (PSYPHER)** is a service that aims to help young people experiencing psychosis or are at risk of developing psychosis. If you have already attended this service you can contact your Care Coordinator. If you have since been discharged from the service you can call **01482 336786** or contact your GP.

Alternatively you can contact the **Early Intervention Team** in Barnsley which is a similar service for young people. If you would like to attend this service you can call **01226 644166** or contact your GP.

ReThink also offer support groups for carers. If you would like to find a group in your local area you can find out more on their website:

www.rethink.org

If you are experiencing severe difficulties and urgently need support, please contact the **Humber Mental Health Response Service.** This service operates 24 hours a day, 7 days a week for individuals who have a GP in the Hull or East Riding area. To contact them please call **01482 301701.** They are based at:

Miranda House, Gladstone Street
Anlaby Road
Hull, HU3 2RT

Alternatively, if you are not in the Hull and East Riding area you can contact the **Barnsley Single Point of Access** on **01226 645000.** They are open from 8am to 8pm Monday to Friday and from 8am to 4pm on Saturday and Sunday. They are based at:

Littleworth Court, Littleworth Lane
Lundwood
Barnsley, S715RG

Should you have any specific issues regarding your treatment that taking part in this study has raised then you can call the Researcher on:

07956601485

If you still have concerns having spoken to the Researcher it is recommended that you seek advice from your GP.

Date: 10/04/2018
Version Number: 1.1
IRAS ID: **242096**

Appendix K: Example of data analysis

Transcript	Initial Commentary	Initial Codes
I: Yeah. So it felt… it felt more manageable as a situation than if we had just ignored it and not… <u>I think as soon as we found out she was sort of feeling depressed we were quite proactive in sort of getting the help and pushing it further</u>. I think Lucy… I don't know if she felt she could talk to us or I think it's just hard being a teenager so she went down that route. She wouldn't admit it at first but she properly sort of benefitted from talking to us about it and it helping. So it was… we was quite sort of… as soon as someone recommended going to the CAMHS and just having a psych … just an assessment to see if there was a chance of psychosis we were quite sort of willing to go down that route just because we weren't sort of, in denial about what was going on. I mean I can't determine how Lucy really feels inside so it's not for me to assess so it was actually quite good that there was somewhere to go and that to actually help in that situation so it was quite... <u>because I think one of the things I felt is a bit powerless like to help her because as a parent you want to sort of fix it and it's not something I necessarily had the skills to do so</u>. In that sense it's been positive sort of experience in sort of dealing... Having someone who can actually manage it from the outside and help us.	ARMS made the situation feel more <u>manageable</u> –she was getting support and they knew what the problem was. Proactive in seeking help for Lucy – 'pushing it further' taking back some control? Feeling responsible as a parent? Benefit of talking to others about her experiences – experience of open communication Looking for answers and a diagnosis 'it's not for me to assess' - <u>idea of responsibility</u> – who's role is it? Relief that there was somewhere to go that could help – shared responsibility? Reduced burden? Feeling <u>powerless</u> as a parent – wanting to fix the situation but <u>not having the skills</u> to help – there is a 'correct' way of helping	Feeling supported Being proactive in seeking help Open communication Seeking help Responsibility – Need to be qualified Relief/Reassurance Feeling powerless

	It has been positive having someone outside of the family who can help to <u>manage</u> the situation	Services as powerful
G: How was it feeling that there was somewhere you could go?		
I: It just, it <u>felt like the process was being fixed</u>, she was being dealt with, she was being treated which was a big relief because when I first found out she was sort of feeling the way she was, you just want to ask her questions, and you wanna bombar...you feel like you want to get the answers and you want to sort of help her but it's not something... as I say <u>I'm not qualified or trained to do that sort of work</u> so actually having someone there doing it who's helping her sort of <u>takes a bit of the pressure off ourselves as parents,</u> just sort of knowing that she's getting the help she needs. It was sort of quite <u>reassuring</u>. It felt like it was quite a <u>quick process.</u> I mean it's probably gone on over a year but it's not been a case of its started a year ago and it's only just started it's been a <u>slow process</u> and it's been...so it did feel like it was moving quite smoothly and [pause]... she sort of like... I think we dealt with it better at first than what sort of Lucy has. Lucy has probably taken her 7 or 8 months to see the benefits but I probably, me and her mum started to notice them within a few months. I think the idea of talking about things, Lucy doesn't necessarily see <u>how that would benefit talking to me and her mum</u> but actually whether she thinks that now or not, she does. Whether she realises that	Sense of <u>relief</u> that there was a process underway and Lucy was being treated 'fixed' – perceived as broken before? Wanting to help but not having the <u>skills to do so</u>. Looking for answers Belief that they need someone qualified in this area to help <u>Relieves</u> pressure from parents knowing that she is being helped Both a quick and slow process? Moving smoothly – opposite to previous experience? Took Lucy a while to find FT beneficial as didn't see *benefit of talking* but parents noticed benefits more quickly – talking about things is beneficial	Relief/Reassurance Looking for answers Powerless Getting support Responsibility Relief/Reassured Getting support Importance of communication

she's actually talking to us about more things and being open, she's crossed a barrier. I think it's easier to talk to people who are strangers than people you are close to. I think one of the things of when she was first talking to a counsellor, it was one on one and she didn't have to talk to us. But when it was with "Jim" at CAMHS we was in the room and she wasn't comfortable with that but actually, see that helped me with the process then because I was involved. Even if I wasn't necessarily doing anything to help, just being involved in the process which is what I didn't necessarily like about the counselling was maybe she would give you a five minute brief at the end of what was said but she wouldn't say much and she was really quite protective about what her and Lucy had spoke about so that was more frustrating. So actually what I found positive about going to CAMHS and doing the family stuff was it actively involved us so for the actual assessment we would be sat there while Lucy was answering the questions and maybe we could help her get the answers out. And then she would still have a one on ones with "Jim", I think she maybe has one today, but then the family stuff as well which really helped me as well as… to deal with it because it was a shock for me and her mum to find out that she was actually feeling that way.	FT led to improved communication – now more open with her parents. 'crossed a barrier' – barriers in the journey? Does it also suggest there are more ahead? Easier to talk to strangers than people you are close to – opening up is harder with family Benefit of being involved – helping to gain skills 'wasn't necessarily doing anything to help' Confidentiality was difficult for parents – powerless He found process beneficial because he was involved He felt left out when it was one on one because he didn't know what was being discussed – lack of control? Powerlessness? Feeling actively involved during FT – helped parents with the shock of ARMS	Communication Communication Noticed improvement Opening up with professionals Communication Powerless Powerless Communication Involved – getting support Powerless Involved vs excluded Emotional reaction to ARMS

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Appendix L: Ethical Approval

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