THE UNIVERSITY OF HULL

Family Experiences of First Episode Psychosis

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By Emily Thornhill, BSC (Hons) Psychology, University of York

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Overview

This portfolio thesis consists of: a systematic literature review, an empirical paper and appendices. The thesis considers the influence of early psychosis on relationships within families.

Part one is a systematic literature review exploring how family relationships are influenced by first episode psychosis (FEP). The review utilised the NICE quality checklist to evaluate research papers, determining the final included papers which were ultimately subjected to a narrative synthesis. Findings demonstrated the influence of psychosis and identified themes of progressive changes as well as the difficulties encountered within family relationships. Potential future research and clinical implications of findings are discussed.

Part two is an empirical study of care coordinators' perceptions of family growth associated with a FEP. Eleven care-coordinators participated in semi-structured interviews and transcripts were analysed using social constructivist grounded theory. Findings described key aspects of growth and how it may be inhibited within some families. The findings are discussed thoroughly alongside previous literature and implications and avenues for future studies are described.

Part three contains appendices that are relevant to both the systematic literature review and empirical paper. It includes a reflective statement of the process of completing the research and review, and an epistemological statement that describes the position of the researcher.

Total word count: 11, 686 (including tables, appendices and references)

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Part One: **Systematic Literature Review**

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

Psychosis

Please see Appendix C for submission guidelines

The Influence of First Episode Psychosis on Family Relationships

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Abstract

Objective: First Episode Psychosis (FEP) has a significant impact on family members and relationships within the family. The aim of this paper is to provide an up-to-date, rigorous and systematic review of literature that describes how family relationships are influenced by FEP.

Method: The literature was searched systematically using: Academic Search Premier, CINAHL Complete, MEDLINE, APA PsycArticles, APA PsycInfo between October 2019 and December 2019. Six articles met the inclusion criteria out of 879 found. Data were synthesised using narrative synthesis.

Results: Findings suggested two broad themes that describe the influence of FEP on family relationships. These include: progressive changes within relationships and difficulties encountered within relationships. The progressive changes consist of role changes within the family and enhanced closeness and cohesiveness. The difficulties encountered consist of frustrated and resentful relationships, fragility due to tension within relationships and distance within or loss of relationship.

Conclusions: The review demonstrates how family relationships are influenced by FEP in a variety of ways. It emphasises the importance of family inclusive working and the need for normalising relational changes that may occur. The progressive changes experienced within relationships also highlights an area for future research into family growth and how it can be promoted.

Keywords: first episode psychosis, early psychosis, family, relationships, systematic review

Introduction

FEP (first episode psychosis) is characterised by distressing unusual experiences, such as hearing voices, or beliefs that are not cohesive with societal norms (Cooke, 2007). Experiences vastly differ between individuals, and those with lower associated distress levels may not consider themselves as requiring a diagnosis or professional support from mental health services. Despite this, those who receive a diagnosis of FEP are described as being in a critical period, in which early input is a necessary predictor of positive outcome (Birchwood, Todd & Jackson, 1998). FEP is known to have a significant impact on family members and relationships; distress and difficulties within the family are experienced, regardless of whether the relative with FEP is living with them (Addington et al., 2003). The influence of FEP on family relationships drives family interventions, which are recommended as they are clinically more beneficial than standard care in reducing relapse rates and hospital admissions (Bird et al., 2010).

This paper aims to explore the influence of FEP on family relationships. The author acknowledges that “family” is a social construct, which Trost (1990) states is impossible to define since perspectives are varied. Trost (1988) proposed that for ease, research could define family as “consisting of at least one parent-child unit and/or at least one spousal unit”. This paper widens this definition and includes grandparent and sibling relationships, but also appreciates that families across the world are exceptionally diverse.

Most young people who experience a FEP tend to be living at home with their parents (Addington & Burnett, 2004). The family life cycle theory proposes that older adolescents with FEP may be shifting towards independence, causing a transition in the family lifecycle which disrupts family dynamics and contributes to unusual experiences (McGoldrick, Carter

& Garcia-Preto, 1999). This theory is an updated version of Carter & McGoldrick's (1988) original theory and is inclusive of divorce and same sex couples. It demonstrates how psychosis is influenced by changes in family relationships, however, may be considered reductionist in implying a direct causation between psychosis and transition between life stages.

There is likely a reciprocity of influence between family relationships and psychosis; Bateson (1979) termed this "circular causality", whereby patterns of communication within these relationships maintain the influence on both individuals with unusual experiences and family members. This is well described within expressed emotion literature that describes how psychosis and high expressed emotion within family relationships (criticism, hostility and/or overinvolvement) leads to increased relapse rates and higher levels of depression and anxiety which may lead back to high levels of expressed emotion (Bebbington & Kuipers, 1994; Kuipers et al., 2006).

Hence, family relationships are significantly influenced by the presence of a FEP. Siblings report feeling overwhelmed. Their relationship with their sibling changes as they encourage more normalising social activities for the sibling with FEP and their role within the family changes to one of providing support to parents (Sin, Moone & Harris, 2008). A change in role is felt by parents where they become carers for their relative, enhancing feelings of dependency, and impacting the parent-child relationship (Sin, Moone & Wellman, 2005). Literature describes a loss of control and a grieving for the individual followed by a process of adaptation (Nyström & Svensson, 2004; Jungbauer et al., 2004). Despite the considerable distress and burden of psychosis on family relationships, individuals with unusual experiences can also contribute, both practically and emotionally, enhancing feelings of closeness and love within relationships (Coldwell, Meddings & Camic, 2011; Allman et al., 2018; Lukens, Thorning & Lorher, 2004).

Overall, early psychosis is influenced by family relationships and influences the whole family unit as the close network witness their relative's experiences. This may change relationships, for better or for worse. A literature review of quantitative studies investigating the influence of family functioning on individuals with FEP has been published, however, there have been no known literature reviews that have synthesised and summarised current knowledge of the influence of FEP on family relationships (Koutra et al., 2014). This paper will systematically review literature that considers how family relationships are influenced by FEP, which may inform both families and services of what to expect, and potential areas for intervention.

Methodology

The literature was searched systematically using: Academic Search Premier, CINAHL Complete, MEDLINE, APA PsycArticles, APA PsycInfo between October 2019 and December 2019. Utilising the six databases allowed for a wide scoping of literature across a number of disciplines, enhancing the likelihood of finding relevant research papers. A search was also conducted to ensure that no other systematic literature reviews existed in the same area.

Search terms

Between the lead and secondary researchers (AG and CS), the research question, inclusion and exclusion criteria and search terms were agreed. The final search terms entered into the databases were:

famil* or relative* or carer* or caregive* or partner* or carer* or parent* or sibling* or brother* or sister* or kin

AND

"FEP" or "first episode psychos*" or “first-break psychos*" or “first-identification psychos*” or “early psychos*" or “early psychotic*” or "early onset psychos*" or “first psychos*” or “first psychotic*” or “early psychotic*” or “initial psychos*” or “initial psychotic” or “early schizophrenia”

AND

Relationship* or Marriage* or interrelationship* or kinship* or closeness or connection*

Academic journals and English language were the two search limiters applied, ensuring the articles would be peer reviewed, ensuring its quality and that they could be read and understood by the author.

Selection Strategy

Duplicates were removed from the retrieved papers and remaining papers were screened by their titles. If suitability for the review was unclear from the title alone, the reviewer read the abstract or full article. In order to meet inclusion criteria, papers had to:

- Refer to the influence of psychosis on family relationships, reflected in the results section of the paper. At least one quote within a paper, with a focus on family relationships, was enough for the paper to be included.

- Use qualitative methodology, as the review required in depth narratives of experiences, which when analysed should help to provide a detailed picture of how psychosis can influence family relationships.
- Be published after 1990, since early intervention for psychosis gained prominence and recognition in the 1990s (Falloon, 1992).

The results from the databases were screened and papers deemed suitable were read in full. Their reference lists were also screened, and papers were excluded if they did not meet the inclusion criteria. Figure 1 illustrates the paper selection process.

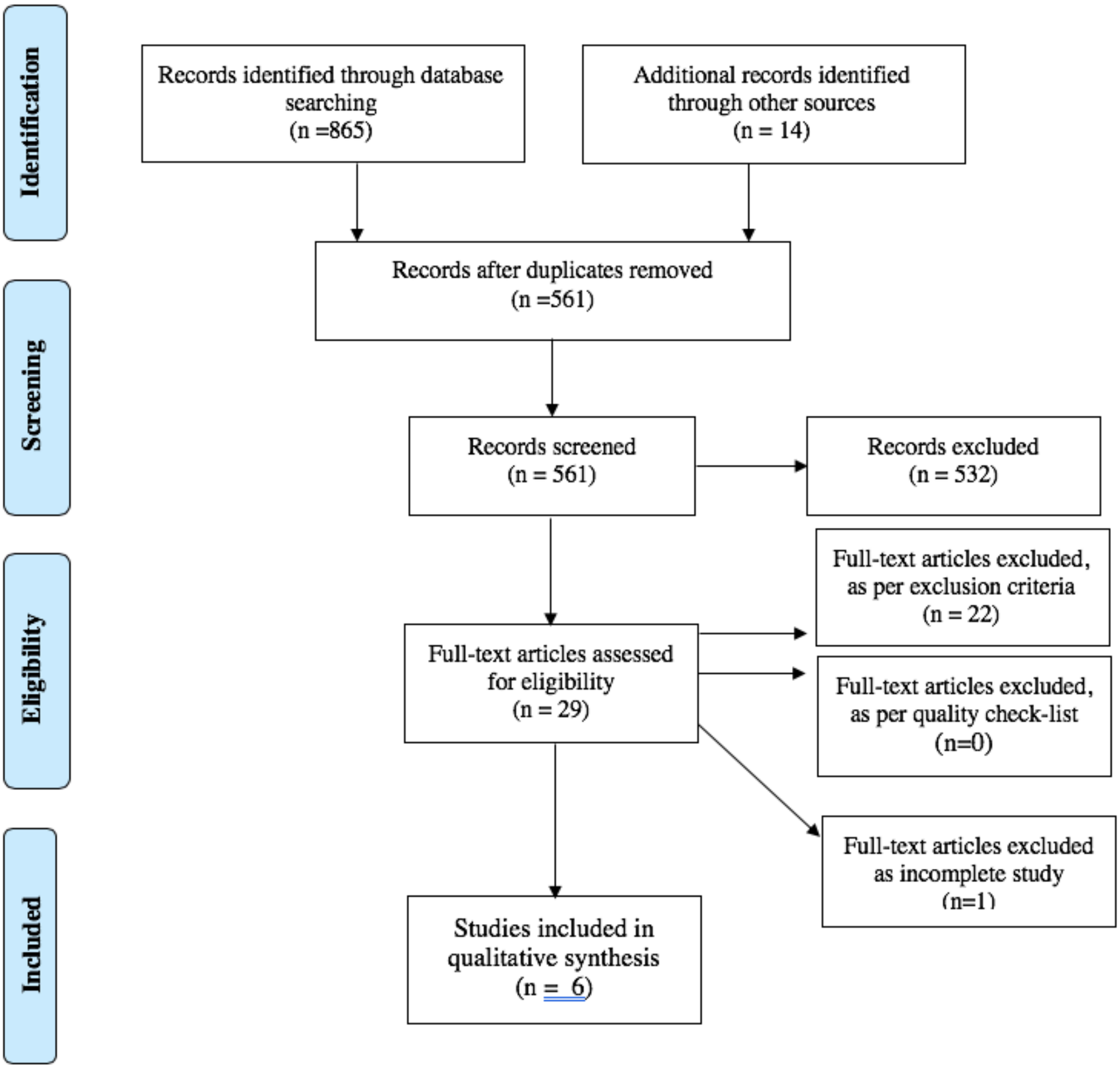


Figure 1. A diagram to represent the process of selection of relevant papers from databases.

Data extraction and Quality Assessment

Relevant data from each study was extracted from each selected paper. This included the location of the study, methodology, information about the participants and key findings. Alongside this, the National Institute for Health and Care Excellence (NICE) quality appraisal checklist was used to assess the quality of each study (NICE, 2012; See Appendix D). This is a quality checklist used for studies that collect and analyse qualitative data. The questions on the checklist acknowledge the variety of ways in which qualitative research is conducted and assigns "++" for studies that meet all or most of the quality criteria. If a study met some of the criteria and conclusions would remain the same regardless, it would be scored "+". If a study met few or none of the quality criteria, the paper is assigned a score of "-". This checklist was selected as it is a simple tool that asks all relevant questions for the review. Other checklists such as the "Evaluative Tool for Qualitative Studies" may have been appropriate, however, the simplicity of the NICE quality checklist scoring system was deemed most efficient. See appendix E for the summary table that outlines the included studies along with their quality score.

Results

Overview

Overall, six studies were included in the review (see Table 1 for an outline of these studies). These papers were published between 2001 and 2019 and all utilised qualitative methods. For data collection, all authors used semi-structured interviews and only one (Wainwright et al., 2015) interviewed focus groups.

Two studies (Newman, Simonds & Billings, 2011; Sin et al., 2012) recruited sibling participants. The four remaining studies (Wainwright et al., 2015; McCann, Lubman & Clark, 2011; Onwumere et al., 2019; Hickman et al., 2016) recruited other family members including parents, grandparents, spouses, aunts and uncles. All of the included studies provided data about the number and type of relative who participated in their research. All studies apart from McCann, Lubman & Clark (2011) took place in England. McCann, Lubman & Clark (2011) conducted their research in Australia.

Quality of Studies

According to the NICE Qualitative Assessment Checklist (NICE, 2012; See Appendix D) all studies were found to be of sound quality, each gaining scores of "++". Authors used appropriate methods in an ethical manner and provided rich and eloquent descriptions of the interviews, helping to provide the reviewer with good insight into the processes that families undergo when a relative experiences FEP.

It was noticeable however, that all papers but Hickman et al., 2016 inadequately described the role of the researcher and the relationships between them and the participant. This demonstrates some lacking transparency and awareness of power relations, which is deemed very important to acknowledge in qualitative clinical research (Karnieli-Miller, Strier & Pessach, 2009). Acknowledging researcher's backgrounds enables reflexivity whereby the lens through which data analysis was conducted is carefully considered. Despite this, the overall assessment of the studies deemed them all to be thorough and reliable and were therefore included into the current review.

Table 1. Overview of included studies.

Author and Year	Location	Method	Participants	Key Findings	Quality Rating
Hickman, Newton, Fenton, Thompson, Boden & Larkin (2016)	England	Interpretative phenomenological analysis: Semi-structured interview	Six parents of service users who had been hospitalised with early psychosis and were currently under the care of a Midland' early intervention service	1) Accepting and blaming a) Where a non-blaming position was taken, parents were more positive towards the young person and normalised behaviours which may have contributed to psychosis b) Parents with a more critical and blaming perspective understood psychosis as being related to external factors 2) a) Hospital provided a relief from the burden of caring Hospitalisation as also accompanied by distress at feeling blamed by their child	++
McCann, Lubman & Clark (2011)	Australia	Interpretative Phenomenological Analysis: Semi-structured Interview	Twenty first-time primary care-givers to young adults diagnosed with FEP (17 participants were female and there was a mean age of 49 years overall). Majority of participants were parents (85%) but	1) Feeling responsible for their illness a) Generalised feeling of responsibility b) Conflict in household if other family members blame primary caregiver when something goes wrong for person with FEP 2) Coming to terms with the change a) Accepting the change: Mourning the loss of the previous relationship and accepting the young person's circumstances	++

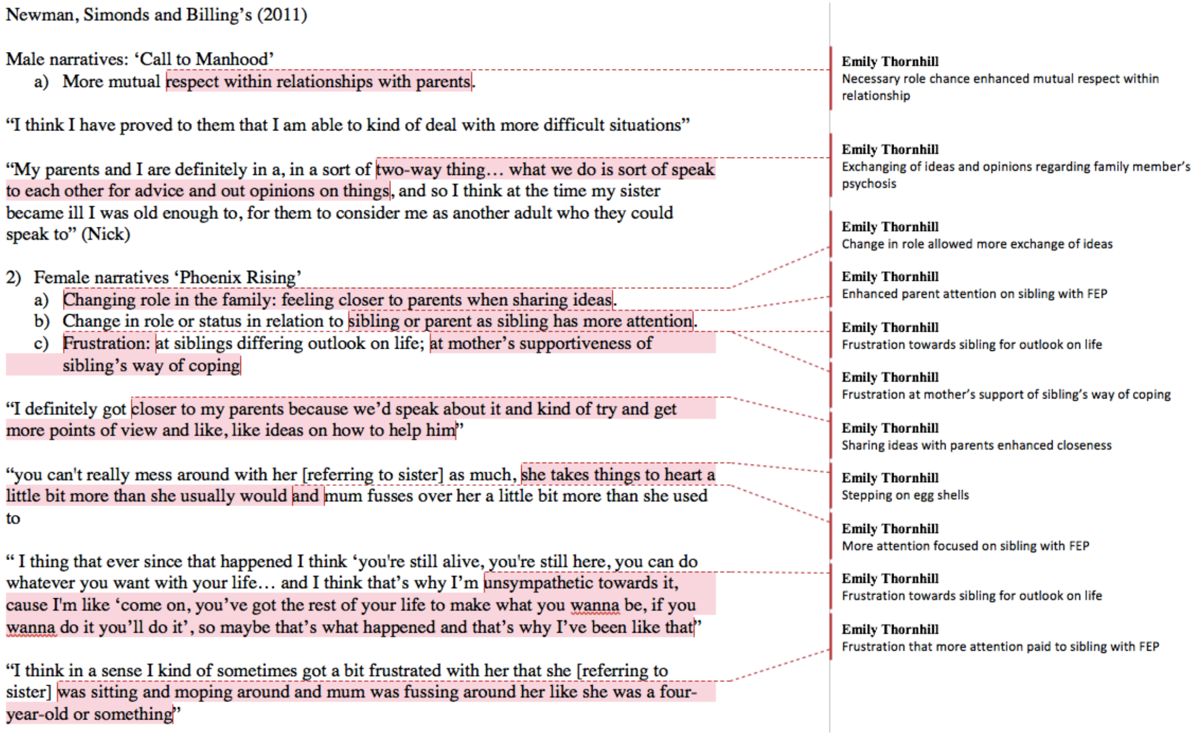
			sample also included a grandparent, a spouse and an aunt/uncle.	b) Caregivers accepting their circumstances: long-term role change e.g. from being a mother to a carer. 3) Becoming closer a) Strengthening already good relationships b) Or in relationships not previously very close, a bringing together in closer, more open and deeper relationships c) Relationships bound through honesty, trust, caregiver showing genuine interest in and attempting to understand the young person	
Newman, Simonds & Billings (2011)	England	Narrative Analysis: Semi-structured Interview	Four Siblings of an individual with FEP: Two males, two females.	1) Male narratives: 'Call to Manhood' a) More mutual respect within relationships with parents. 2) Female narratives 'Phoenix Rising' a) Changing role in the family: feeling closer to parents when sharing ideas. b) Change in role or status in relation to sibling or parent as sibling has more attention. c) Frustration: at siblings differing outlook on life; at mother's supportiveness of sibling's way of coping	++

Onwumere, Parkyn, Learmonth & Kuipers (2019)	England	Interpretative phenomenological analysis: Semi-structured interview	Eight carers identified from early intervention in psychosis team known to have been exposed to violence from their relative with FEP (six mothers, one father and one grandmother)	Changing relationships: carers spoke of their enduring love for their relative, but others spoke of the gradual distancing and separation within relationship	++
Sin, Moone, Harris, Scully & Wellman (2012)	England	Thematic Analysis: Semi-structured interview	31 Siblings of service users treated by local EIPS in Berkshire and West London (22 Female and 9 Male)	1) Siblings roles and involvement a) Providing companionship and including sibling in own circle of friends b) Younger siblings aged 11-16 years reported tensions caused by FEP and coped by keeping a low profile 2) Diverse emotional responses a) Siblings felt resentment towards their unwell sibling for taking parent's attention. b) Siblings felt they had lost their unwell sibling as they had different character since psychosis 3) Impact on relationships a) Closer sibling bond b) Positive changes in family relationships overall as communication improved and became able to address problems together	++

				c) Some siblings distanced from their unwell sibling and felt that there was less family contact than previously d) Concern for younger siblings and difficulty explaining psychosis to them e) Sibling's psychosis caused siblings to question perspectives of future relationships and raising children	
Wainwright, Glentworth, Haddock, Bentley & Lobban (2015)	England	Thematic Analysis: Semi-structured Interview	Four focus groups each with a range of five to seven participants. Total of 23 participants who had a relative with psychosis. Twenty-two were parents (12 mothers) and the other was the husband of a woman experiencing "bipolar tendencies".	Understanding and managing effects of psychosis: 1)Psychosis from the relative's perspective: a) their difficulty understanding perhaps due to strained relationships caused by communication breakdowns b) Marital strain due to differences in responses and management of psychosis.	++

Thematic Synthesis

The reviewer approached analysis of the data using thematic synthesis following the guidelines set out in Thomas and Harden (2008). A thematic synthesis allows the identification of themes across qualitative studies and draws upon well established thematic analysis techniques. Figure 2 shows an example of line by line coding from relevant sections of the findings in Newman, Simonds and Billing's (2011) study and Table 2 shows an example of the how themes were derived from these codes. The question of how FEP impacts relationships within the family can be understood by two broad themes outlined in Table 3 : 1) The progressive changes within family relationships associated with a FEP and 2) The difficulties encountered within family relationships associated with a FEP.



Newman, Simonds and Billing's (2011)

Male narratives: 'Call to Manhood'
   a) More mutual respect within relationships with parents.

"I think I have proved to them that I am able to kind of deal with more difficult situations"

"My parents and I are definitely in a, in a sort of two-way thing… what we do is sort of speak to each other for advice and out opinions on things, and so I think at the time my sister became ill I was old enough to, for them to consider me as another adult who they could speak to" (Nick)

2) Female narratives 'Phoenix Rising'
   a) Changing role in the family: feeling closer to parents when sharing ideas.
   b) Change in role or status in relation to sibling or parent as sibling has more attention.
   c) Frustration: at siblings differing outlook on life; at mother's supportiveness of sibling's way of coping

"I definitely got closer to my parents because we'd speak about it and kind of try and get more points of view and like, like ideas on how to help him"

"you can't really mess around with her [referring to sister] as much, she takes things to heart a little bit more than she usually would and mum fusses over her a little bit more than she used to

" I thing that ever since that happened I think 'you're still alive, you're still here, you can do whatever you want with your life… and I think that's why I'm unsympathetic towards it, cause I'm like 'come on, you've got the rest of your life to make what you wanna be, if you wanna do it you'll do it', so maybe that's what happened and that's why I've been like that"

"I think in a sense I kind of sometimes got a bit frustrated with her that she [referring to sister] was sitting and moping around and mum was fussing around her like she was a four-year-old or something"

Emily Thornhill
Necessary role chance enhanced mutual respect within relationship

Emily Thornhill
Exchanging of ideas and opinions regarding family member's psychosis

Emily Thornhill
Change in role allowed more exchange of ideas

Emily Thornhill
Enhanced parent attention on sibling with FEP

Emily Thornhill
Frustration towards sibling for outlook on life

Emily Thornhill
Frustration at mother's support of sibling's way of coping

Emily Thornhill
Sharing ideas with parents enhanced closeness

Emily Thornhill
Stepping on egg shells

Emily Thornhill
More attention focused on sibling with FEP

Emily Thornhill
Frustration towards sibling for outlook on life

Emily Thornhill
Frustration that more attention paid to sibling with FEP

Figure 2. Line by line coding for Newman, Simonds and Billing's (2011) study.

Table 2. Example of derived subthemes and themes from Newman, Simonds and Billing's (2011) study.

Code	**Associated subtheme**	**Associated Broad Theme**
Necessary role chance enhanced mutual respect within relationship	Changed roles and mutual respect	Progressive changes within family Relationships Associated with FEP
Exchanging of ideas and opinions regarding family member's psychosis	Changed roles and mutual respect	Progressive changes within family Relationships Associated with FEP
Change in role allowed more exchange of ideas	Changed roles and mutual respect	Progressive changes within family Relationships Associated with FEP
Enhanced parent attention on sibling with FEP	Frustration and resentment within relationship	Difficulties Encountered within Family Relationships Associated with FEP
Frustration towards sibling for outlook on life	Frustration and resentment within relationship	Difficulties Encountered within Family Relationships Associated with FEP
Frustration at mother's support of sibling's way of coping	Frustration and resentment within relationship	Difficulties Encountered within Family Relationships Associated with FEP
Sharing ideas with parents enhanced closeness	Enhanced closeness and Cohesiveness	Progressive changes within family Relationships Associated with FEP
Stepping on egg shells	Fragility within relationships	Difficulties Encountered within Family Relationships Associated with FEP
More attention focused on sibling with FEP	Frustration and resentment within relationships	Difficulties Encountered within Family Relationships Associated with FEP
Frustration towards sibling for outlook on life	Frustration and resentment within relationships	Difficulties Encountered within Family Relationships Associated with FEP
Frustration that more attention paid to sibling with FEP	Frustration and resentment within relationships	Difficulties Encountered within Family

Table 3. Changes in family relationships associated with FEP.

Broad Themes	**1. Progressive changes within family Relationships Associated with FEP**	**2. Difficulties Encountered within Family Relationships Associated with FEP**
Subthemes	1.1 Role Changes: creating mutual respect between siblings and parents	2.2 Frustrated and resentful relationships: due to parental attention being taken away from siblings, critical appraisals of psychosis if viewed as being self-inflicted
	1.2 Enhanced Closeness and Cohesiveness: openness and sharing of ideas and emotions plus enhanced understanding	2.2 Fragility within relationships due to tension: walking on egg shells, trying not to annoy the individual; arising conflict when differences in managing and coping with individual with FEP
		2.3 Distant or Loss of relationship: loss due to change in character of individual with FEP; blame also contributing to

	distancing within relationship.

1. Progressive Changes Within Family Relationships Associated with FEP

This theme highlights the positive changes that occur within families associated with a family member's FEP. These progressive changes include role changes within family relationships creating a positive shift in dynamics, and a sense of enhanced closeness and cohesiveness where families feel more open with each other.

1.1 Role Changes

Interviewees spoke about the role changes experienced within their families (Newman, Simonds & Billings, 2011; McCann, Lubman & Clark, 2011; Sin et al., 2012). In Newman, Simonds and Billing's (2011) study siblings spoke about enhanced mutual respect within the parent-sibling relationship where they no longer considered themselves as being in a child-like position within the family.

> *"My parents and I are definitely in a, in a sort of two-way thing… what we do is sort of speak to each other for advice and our opinions on things, and so I think at the time my sister became ill I was old enough to, for them to consider me as another adult who they could speak to."*
>
> *(Newman, Simonds & Billing, 2011, p. 8)*

Siblings spoke about how their role required them to provide companionship for the sibling with unusual experiences, by inviting them to socialise within their peer groups and encourage their family member to engage in more meaningful activities (Sin et al., 2012).

> *"I think part of it is now trying to get him happy and stuff. And I've been taking him to social activities and taking him to the gym, and spending extra time with him. It helps."*
>
> *(Sin et al., 2012, p. 55)*

Despite these positive changes within relationships, one study acknowledged the weight of responsibility within the role of supporting a family member with FEP (McCann, Lubman & Clark, 2011).

> *"It's quite a heavy responsibility, because as a mother you feel that it is your role to look after your children, and even if I have my husband and the whole family is involved, you are the main character in this"*
>
> *(McCann, Lubman & Clark, 2011, p. 383)*

Thus, as the roles changed within the families, so did the responsibilities, however these changes were perceived to be progressive in that they further influenced communication within families, which seemed to ultimately influence the family's sense of closeness.

1.2 Enhanced Closeness and Cohesiveness

Four of the included studies spoke about an overall sense of enhanced closeness and cohesiveness within their family, associated with their family member's FEP (Newman, Simonds & Billings, 2011**;** McCann, Lubman & Clark, 2011; Sin et al., 2012; Onwumere et al., 2019). This quote describes how, despite the difficulties endured, relationships deepened and became closer.

"I guess it has given depth to the relationship. It's been a pretty 'crap' [difficult] time sometimes. There's had to be a bit of honesty and recognition of each other as individuals, and honesty about how both of our behaviours have affected the other person. So there's been a closeness, but it's been hard going."

(McCann, Lubman & Clark, 2011, p. 384).

This strengthening within family relationships seemed to have been enabled by family members feeling safe to be more open with each other. The increased sharing of ideas, thoughts and feelings encouraged more understanding relationships (Newman, Simonds & Billings, 2011; McCann, Lubman & Clark, 2011; Sin et al., 2012; Onwumere et al., 2019).

"*I definitely got closer to my parents because we'd speak about it and kind of try and get more points of view and like, like ideas on how to help him."*

(Newman, Simonds & Billings, 2011, p. 10)

A carer stated that the violence that they were exposed to as a result of their family member's unusual experiences made them *'understand each other a lot more'* (Onwumere et al., 2019, p. 11). They stated that they wished their family member would not express their needs through violence, but that in some ways it helped them '*understand what he really needs, what he wants',* which may not have happened without the presence of FEP. This demonstrates that despite the adverse experiences, relationships can still become closer and more cohesive through a process of being open and more understanding of each other.

2. Difficulties Encountered within Family Relationships Associated with FEP

This theme highlights the difficulties experienced within family relationships when a relative experiences FEP. The difficulties include frustration and resentment, fragility within relationships and a sense of distance or loss.

2.1 Frustrated and resentful relationships

Individuals described frustration and resentfulness within relationships as a result of the presence of FEP. In particular, siblings described resentment towards their sibling with FEP as they demanded more attention from their parents, taking their attention away from them (Newman, Simonds & Billings, 2011; Sin et al., 2012).

> *"I think in that sense I kind of sometimes got a bit frustrated with her that she [sister] was sitting and moping around and mum was fussing around her like she was a four-year-old or something"*
>
> *(Newman, Simonds & Billings, 2011, p. 11)*

Siblings felt frustrated by the sibling with FEP and their negative outlook on life and felt irritated by the way in which they felt their parent supported this particular way of coping (Newman, Simonds & Billings, 2011).

"I think that's why I'm unsympathetic towards it, cause I'm like 'come on, you've got the rest of your life to make what you wanna be, if you wanna do it you'll do it', so maybe that's what happened and that's why I've been like that"

(Newman, Simonds & Billings, 2011, p. 11)

2.2 Fragility within relationships due to tension

Family members described tension within relationships where they feel as though they are *"walking on eggshells",* trying not to annoy the individual who is experiencing psychosis (Sin et al., 2012; Newman, Simonds & Billings, 2011; Wainwright et al., 2015; Onwumere et al., 2019). Tension is exacerbated when certain family members did not feel safe to be alone with an individual, due to a fear of violence.

"Yes I try to help… [but] it's like walking on egg-shells all the time, I just need to be careful about what to say. I don't ask her lots of questions and I don't annoy her."

(Sin et al., 2012, p. 55)

Furthermore, fragility within relationships is also highlighted by arising conflict that occurs as a result of the heightened pressure and different coping styles (Wainwright et al., 2015; Sin et al., 2012; McCann, Lubman & Clark, 2011).

"Everybody was just so… I don't know… emotions were so hyped up, so high and so ready to boil over that we didn't know how to control it as we just took it out on anyone that we could"

(Sin et al., 2012, p. 56)

2.3 Distant or loss of relationship

Family members described a sense of loss, where they felt they were grieving the loss of their relative's original character or personality due to FEP (Sin et al., 2012; McCann, Lubman & Clark, 2011).

"He's just become a completely different person in the last two years… Now he's just tired, lethargic, lacks ambition, has no drive, no direction. It's like there's nothing there, like his personality has been erased."

(Sin et al., 2012, p. 56)

"I probably mourn the loss in the relationship that I did have with her because it's no longer the same relationship."

(McCann, Lubman & Clark, 2011, p. 384)

As well as loss, distance within relationships was described as family members did not wish to spend time alone with the individual with FEP. Stigma seemed to play a part in causing family members to become fearful (Wainwright et al., 2015).

"A lot of it is educating people in general, even your own family. I've only got one sister and she was scared of, I wanted her to spend time with him on his own and she 'oh err I'm not sure about that' but why?!"

(Wainwright et al., 2015, p. 114)

Distance within relationships was also described as being a result of blame (Wainwright et al., 2015; McCann, Lubman & Clark, 2011; Hickman et al., 2016). Some family members blamed the individual for developing psychosis and blame also occurred within relationships when something went wrong for the person with FEP.

> *"It's very hard because when he tried to kill himself my husband blamed me. "where were you?" he said. I said "What do you mean, where were you? Where were you?".*
>
> *(McCann, Lubman & Clark, 2011, p. 384)*

Distancing also occurred as a result of aggression within the family, where violence towards a family member may have occurred because the individual with FEP felt that their relative is to blame for their situation (Onwumere et al., 2019).

> *"It [aggression] affected it a lot because now we can't even talk. We can't be friends. Because he thinks I'm his enemy, so we can't have a relationship. We don't talk too much because he gets annoyed"*
>
> *(Onwumere et al., 2019, p. 7)*

Discussion

The aim of this review was to synthesise narratives that describe how family relationships are influenced by FEP. The results are described by two broad themes, where families experience both progressive changes and challenges within relationships.

There are progressive changes experienced within the family where there is an enhanced sense of closeness and cohesiveness within their relationships. This occurs alongside role changes within the family, for example, where siblings take on more responsibility in terms of providing more support for parents. This change in role opened up communication, especially between parents and siblings, where there was increased respect for each other's ideas, thoughts and emotions. Therefore, the change in role creates a positive shift in relationships, which reflects a different perspective to that of Sin, Moon & Harris (2008) where siblings described feeling emotionally overwhelmed by the experiences within the family, however, this was an incomplete study whose full findings are described in Sin et al., (2012) . The role change could be an example of the sibling moving from a childlike position, to one with more responsibility. The presence of psychosis may have encouraged family life cycle movement, where parents feel more able to "launch" the sibling and encourage their independence in an attempt to reduce the burden of care that they may feel (Mcgoldrick, Carter & Garcia-Preto, 1999).

Siblings described how their role changed to one of providing companionship and encouraging their sibling with FEP to engage in social activities. This mirrors Sin, Moone and Harris's (2008) findings and demonstrates the importance of maintaining integration of individuals in their community, but also highlights the load and pressure that this can place on family relationships. Thus, despite the role change and enhanced mutual respect, family members acknowledge the weight of this responsibility. This reflects Sin, Moone and Wellman's (2005) study that investigated carers' needs from an early intervention service where parental accounts described the parental role as enhanced to a carer role, where duties are increased, placing more pressure on them. Despite this, studies described an overall sense of enhanced closeness which is similar to Lukens, Thorning and Lohrer (2004) who explored sibling perspectives of severe mental illness more generally, where relationships between family members felt richer with a deeper sense of love. Strengthened relationships may be related to an opening up of communication where mutual understandings are established. For some, this happened despite adversity such as violence, possibly demonstrating a process whereby positive changes within relationships can occur after a period of discomfort. It mirrors previous findings where individuals with psychosis continue to contribute to their families in terms of emotional support and familial enhancement (Coldwell, Meddings & Camic, 2011).

Whilst the progressive changes within families are reassuring, it is important to acknowledge the challenges that can occur within relationships when an individual within a family has FEP. Siblings reported frustration and resentfulness within their family relationships as parental attention is taken away from the sibling, as the parents' role changes to a more caring position for the individual with FEP (Sin, Moone & Wellman, 2015). The pressure that psychosis places onto the family unit is notable and causes fragility within relationships as tensions rise. Relatives feel that they must tentatively walk on egg shells, to avoid annoying the individual who has FEP due to fear of contributing further to their difficulties. This may limit the ways in which the family communicate with the individual and cause family members to neglect their own needs for those of the relative. Circular causality becomes relevant where communication becomes tense and inadequate, limiting communication of difficulties, which may prevent exploration and resolution within the family, thus, maintaining the problem (Bateson, 1979).

Families also expressed a sense of loss and described a process of grieving for their relative, as their personality changed as a result of psychosis. This was described by Nyström and Svensson (2004) where fathers described a process of grief and struggle before adapting to the new dynamics and norms within family relationships. Jungbauer et al., (2003) described various other losses such as loss of other social contacts outside of the family; they described how psychosis could make parenthood permanent and caused parents to re-evaluate their expectations of their child and their own personal plans. The strain experienced by individuals may contribute towards the expression of blame within relationships. A negative appraisal of the cause of psychosis, caused criticism towards the individual, which is described in expressed emotion literature as contributory to future relapses (Bebbington & Kuipers, 1994). Blame occurs within the other relationships too, where parents might blame each other if an individual with FEP harmed themselves. This blame could be interpreted as being the product of Nyström and Svensson's (2004) description of family members attempting to seek answers but may also contribute to further distress and difficulties experienced within the family relationships (Addington et al., 2003).

Assessment of strength of the review

Overall, the quality assessment of the papers demonstrated good quality of research. It is possible that since research into FEP has gained momentum, the quality of such research has been prioritised as all papers utilised ethical methods of data collection which yielded rich data and convincing results. However, all but one paper failed to clearly describe the role of the researcher which meant that the relationships between the researcher and the participants were unknown. This relationship may have influenced how participants responded during their semi-structured interviews.

Furthermore, all but one study was conducted in England. McCann, Lubman and Clark's (2011) research was conducted in Australia, which inherited a number of ideas and definitions of mental health difficulties from Britain (Shera et al., 2002). Therefore, findings are possibly most relevant to these individualist societies that hold similar definitions of psychosis. The review of these studies would be less generalisable to collectivist societies, which may define FEP and family differently so would likely experience different changes in relationships as a result of FEP. Therefore, the results of the review are potentially less relevant to other cultures.

The strength of the review may be limited by the fact that it describes the differences in multiple types of relationships, for example: individuals with FEP to sibling, individual to parent, sibling to parent. The experiences within, and nature of, each dynamic may be very different, therefore, drawing concrete conclusions about the overall influence of psychosis on family relationships is challenging. Future reviews may consider focusing on the specific relationships, to decipher more idiosyncratic changes that may occur within specific family relationships.

Additionally, the White British female author's upbringing within a western, nuclear family may contribute to cultural assumptions that may influence the interpretation of the findings of the included research. Regular supervision and writing of a reflective journal helped to identify and attended to this influence, particularly throughout the thematic synthesis section of the review.

Wider Implications

This review highlights how family relationships are influenced both positively and negatively by FEP. It demonstrates the complexity of how FEP can influence relationships in various ways and emphasises the importance of family inclusive working, at the earliest possible point, so that families can feel supported and guided through the changes that may occur within their relationships. Normalising psychosis and the changes that may occur within relationships through family peer support groups may also be beneficial.

When there is an abundance of literature that surrounds the negative impact of psychosis, future research should consider exploring contributors towards family growth. Those working in EIP should also remain mindful of the positive changes such as mutual respect alongside closeness and openness within relationships. Family inclusive work may wish to focus on this potential, whilst remaining aware of the frustrations and resentment that may also occur within family relationships. The fragility, distancing or grief between individuals should be met with compassion and sensitivity, to prevent further contribution towards relational tensions.

Conclusion

Family relationships are considerably influenced by the presence of FEP. Families describe progressive changes within the relationships that happen as a result of role changes, which has the propensity to create more mutual respect between parents and siblings as siblings take on more responsibility. Families describe a sense of enhanced closeness and cohesiveness within relationships, where communication is more open and families are able to share ideas and feel more understanding of each other. Families also report feelings of frustration and resentment within relationships, largely as a result of attention being focused on the individual with psychosis, which removes the attention away from siblings. Fragility and tensions within relationships are reported and is dependent on the individual's presentation and ways in which family members cope and manage the difficulties. Distance and loss within relationships is described as FEP changes the character and outlook of the individual experiencing it. This highlights the need for early family inclusion for FEP to encourage the more positive changes within relationships, whilst acknowledging and exploring the potential challenges within family relationships. The findings of the sample should be interpreted with caution, as they represent westernised, individualistic accounts and therefore cannot be generalised across families and cultures.

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Part Two: Empirical Paper

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

Psychosis

Please see Appendix C for submission guidelines

A constructivist grounded theory analysis of care-coordinators' perceptions of family growth associated with an experience of first episode psychosis

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Abstract

Growth associated with a first episode psychosis (FEP) is taken from post-traumatic growth literature, where positive changes are perceived following adverse circumstances. FEP is a critical period in which care-coordinators play a key role in working with families in early intervention for psychosis. Care-coordinators' perceptions influence the way in which they work with families. There is currently a distinct lack of research into care-coordinators' perceptions of family growth associated with FEP. Therefore, eleven care-coordinators described their perceptions of growth within families with FEP through semi-structured interviews. Transcripts were analysed using social constructivist grounded theory. Care-coordinators perceived the existence of family growth in the form of enhanced communication as well as less explicit forms of growth including distancing from unhelpful relationships and a re-establishment of norms and boundaries. Growth was inhibited by the construct of the "perfect family" model, a mis-trust in services due to suspiciousness or prior negative experiences of services. These inhibitors limit engagement with interventions and prevent open exploration of difficulties. Future work may consider how these findings align with the views of families.

Keywords: First episode psychosis, growth, family, care-coordinator, services, social constructivist grounded theory

Introduction

The current research focuses on care-coordinator perceptions of family growth associated with first episode psychosis (FEP). "Psychosis" describes the phenomena of unusual experiences, typically voice hearing or seeing, tasting, smelling or feeling something that others do not and/or having beliefs that are not shared by others; these experiences are commonly termed hallucinations and delusions respectively, although are mostly pathologised when experienced alongside distress (Cooke (2017)). Psychosis could be considered a continuum of experiences where those who experience distress and discomfort are most likely to seek support from mental health services and therefore receive a diagnosis. "Growth" is a term taken from the post-traumatic growth literature and is defined as positive changes experienced alongside or following a FEP (Dunkley & Bates, 2015). This study reflects a positive psychology and collectivist stance and assumes that growth can apply to families as well as individuals, whereby it investigates the positive changes within families associated with FEP.

The movement towards early intervention in psychosis (EIP) began just under three decades ago (Keshavan & Schooler, 1992). This was after the different phases of psychosis were acknowledged from early psychosis, to the critical period, to prolonged psychosis (McGorry et al., 1992). Negative outcomes and cognitive impairments are associated with longer waiting times, demonstrating the importance of detection and intervention at the earliest possible point (Marshall et al., 2005; Caspi et al., 2003). The "critical period" i.e. FEP, provides a key opportunity to prevent relapses (Birchwood, Todd & Jackson, 1998). The National Institute for Health and Care Excellence (NICE) guidance recommends that individuals with FEP and their families are offered family interventions alongside individual therapy and pharmacology (NICE, 2014). EIP services have shorter waiting lists compared to community mental health teams, and care-coordinators within EIP have closer and more frequent interactions with families. Individuals who received support from EIP services demonstrated better outcomes than those who received standard care, however, the long-term effects are unclear (Craig et al., 2004; Bertelsen et al., 2008; Correll et al., 2018).

The emphasis on family involvement in EIP services stems from the significant impact that psychosis has on family systems. Informal carers (mainly family members) are more socially isolated with a reduced quality of life and life expectancy than carers of matched community samples (Hayes et al., 2015). Furthermore, carers for individuals with a diagnosis of psychosis experience more sleep difficulties, pain and anxiety than non-caregivers or caregivers of other disorders (Gupta et al., 2015). The cognitive model of caregiving in psychosis suggests that negative carer appraisals, for example, that the individual is to blame for their psychosis, leads to varied cognitive and affective reactions, such as frustration or criticism of their behaviour. This influences their behaviour towards the individual and services and impacts individual and carer outcomes. The model suggests that interventions should target these family appraisals (Kuipers, Onwumere & Bebbington, 2010).

Despite challenges experienced by relatives, research has also looked into growth associated with psychosis. Individuals described psychosis to lead to self-discovery, a more positive sense of self, renewed life perspective, enhanced engagement with and maintenance of wellbeing and deeper engagement with spirituality (Slade et al., 2019; Dixon et al., 2018). Growth also involved relational changes where individuals felt more able to choose which relationships continued or ended, as well as enhancing the value placed on relationships where one individual described “an incredible closeness” with immediate family and friends (Slade et al., 2019). Families have described psychosis as contributing to a shared sense of family growth with increased patience, tolerance and communication skills which also felt "personally enhancing" (Coldwell, Meddings and Camic, 2011). Those who experienced psychosis made significant contributions within their families and communities in terms of practical support, emotional support, reciprocal exchange and personal and family enhancement (Allman et al., 2018). However, Allman et al's (2018) recruitment was challenging as care-coordinators had difficulty finding participants whom they perceived had "positively contributed" to their families. The cognitive model suggests that care-coordinators' may have held negative appraisals of psychosis and seldom considered positive changes within families, which may ultimately impact how they behave towards individuals with psychosis and their families. Consequently, Allman et al (2018) recommended that research should consider staffs' perceptions as they influence how they might intervene with families.

Family support facilitates positive change (Jordan, Malla & Iyer, 2020). In Finland, this may include other members of the community and friends. Within this forum, all are seen as participants in the problem and are encouraged to discuss all related issues (Seikkula, Alakare & Aaltonen, 2001). All members become an equal part of the network and the expertise is held within the social network, not with one person. Staff can be viewed as witnesses to the journey of families living with psychosis. Their unique position, where they are not a part of the family unit but see how they cope and adjust to the experiences, makes their perceptions valuable when gathering an understanding of how psychosis impacts families.

The abundance of literature regarding burden and challenges associated with psychosis encouraged the current research to gather care-coordinators' perceptions of family growth associated with FEP. Gathering staff perceptions related to FEP is crucial, as this is the critical period of psychosis that predicts prognosis (Birchwood, Todd & Jackson, 1998).

Care-coordinators in EIP services have significant influence because they are the first contact for families, with smaller caseloads and more sustained and assertive communication with families than other community mental health teams (Woodward et al., 2018; Burns et al., 2009). They arguably occupy a powerful position whereby their perceptions influence whether a message regarding growth is given implicitly or explicitly; thus, shaping families' attitudes towards FEP. Furthermore, the relationships between care-coordinators and the individual and their family play a vital role in the individual's recovery making it imperative to understand care-coordinators' perceptions that may mediate these relationships (Watkins, Sanderson & Richards, 2018; Barr et al., 2015; Lester et al., 2012).

The research will contribute to the current pool of literature around family growth associated with an experience of FEP as it will be explored from a different perspective (care-coordinators). This identifies how the concept of "growth" is constructed within staff teams and what factors may facilitate or inhibit growth. Findings may help to suggest an understanding whereby clinicians can comprehend and appreciate the nature of relationships and interactions with clients and their families. It may be useful for clinicians to be mindful of their perceptions of growth to inform them of how they may shape families' sense of hope for their futures.

Method

Design

A qualitative design using semi-structured interviews explored care-coordinators' perceptions of family growth associated with a FEP. A Social Constructivist approach to Grounded theory methodology was employed, where theoretical sampling was utilised, and questions were adapted throughout the interviewing process to achieve depth within participant narratives before ending recruitment at the point of data saturation (Charmaz, 2006; Glaser & Strauss, 1967).

Participants

Eleven care-coordinators were recruited from two EIP services (labelled 1 and 2) located in the North East of England (See Table 1). Participants were aged between 30 and 60 (*M*=41.09, *SD*=10.81). The average number of years working for their service was (*M*=6.23, *SD*= 4.98). Six were female and all were White British. All were assigned pseudonyms to maintain anonymity. Participants were eligible if they a) were care-coordinators and b) had worked closely with families who had a family member experiencing FEP (see Appendices H and I for demographic information sheet and consent forms).

Table 1. Care-coordinator participant information (in order of conducted interviews)

Participant (Pseudonyms)	Gender	Ethnicity	Professional Training	Current Service	Years qualified
Sean	Male	White British	Nursing	1	5
Leanne	Female	White British	Nursing	1	5

Amanda	Female	White British	Nursing	1	5
Amy	Female	White British	Social Work	1	5
Michaela	Female	White British	Nursing	2	19
Mark	Male	White British	Nursing	2	1
Richard	Male	White British	Recovery Worker	2	Not Answered
Kathryn	Female	White British	Occupational Therapy	2	1.5 years
Alice	Female	White British	Not Answered	2	Not Answered
Adam	Male	White British	Nursing	1	20
Rob	Male	White British	Not Answered	2	Not Answered

Procedure

The lead researcher attended the teams' multidisciplinary team meetings to present the research and provide the care coordinators with information sheets (see appendix F). Those interested completed a contact information form (see appendix G) and were subsequently contacted to arrange an interview within two months.

Interviews happened between November 2019 and January 2020. They lasted approximately one hour, were audio-recorded and anonymised during transcription. Interviews were conducted by the lead author following a semi-structured interview schedule (See appendix J for interview guide). The interviewer mostly used open questions that allowed participants to discuss the overall family journeys. Questions became more specific towards the end of each interview where care-coordinators were encouraged to reflect on the existence of growth within the families they had worked with.

A constructivist grounded theory approach to data analysis was selected as it acknowledged that the experiences of families were reflected though the meanings constructed by the language of care-coordinators before being interpreted by the researcher. It meant that constructing meaning from results was an active and iterative process where data was systematically analysed and compared from the start and attention was paid to the language used by participants (Charmaz, 2006; Charmaz, 2014). Descriptive and analytical line-by-line coding of transcripts was done before emerging theories were identified by grouping codes into initial categories and again into broader categories (Charmaz, 2014). Interviews that followed asked questions that related more specifically to the emerging theory. Theoretical sampling was used for the final three participants to further refine categories. Care-coordinators with over eight years working for their service were selected as the previous interviews indicated that those with more experience articulated richer family stories.

A research diary was used throughout the study process to record reflections, ideas and methodological decisions as recommended by Charmaz (2014) and Glaser (1978). Ethical approval was granted from the university and National Health Service research and ethics boards.

Researcher's Position

The constructivist grounded theory approach to data analysis acknowledges that results are a co-construction of ideas where the lead researcher is unable to remain objective without personal values or experiences. Her position is shaped by her own experiences of family connectedness and growth following family illness, or indeed the global Coronavirus pandemic which began alongside final data analyses. Her optimistic lens in relation to the potential for growth in families, meant that the researcher had to place more effort in noticing narratives about families who were less hopeful or optimistic. Furthermore, the researcher's awareness of her own maternally led, nuclear family, meant that she had to pay attention to paternal narratives and the experiences of males. She also had to become more flexible in her personal definition of families, in that they do not just consist of biological parents and siblings.

To minimise these biases, the research supervisors read through a number of transcripts, ensuring that analyses were balanced. Early on, the lead researcher began her reflective statement and thought about areas of potential bias. Despite this, it is acknowledged that the findings from this research may be different had the analysis been conducted by a researcher with a different socio-cultural background or experiences.

Findings

Table 2 summarises the two categories and four subcategories that emerged from the data. A model of emerging grounded theory (Figure 1) depicts how these categories interact and relate to each other.

Table 2. Summary of categories identified from social constructivist grounded theory

Categories	Sub-Categories
Experience of witnessing family growth	**Enhanced communication** - Speaking the unspoken - Finding voice **Less explicit forms of family growth** - Distancing from unhelpful relational dynamics - Setting new norms and boundaries
Prevention of growth	**Family construct of the "perfect family" model** - Being subject to the idea that one must present as a perfect family **Relationship with service** - Mistrust in the service related to prior experience or suspicious beliefs

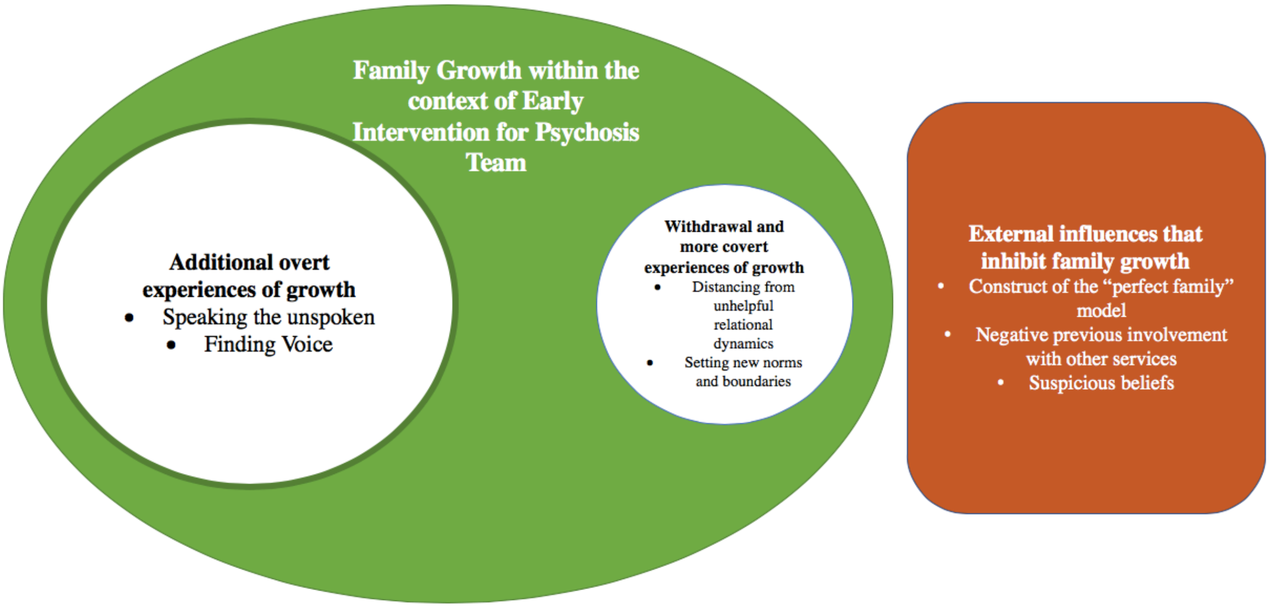

Figure 1. Emerging grounded theory model of how family growth was witnessed and prevented.

1. Care-coordinator's Construction of Family and Growth

See table 4 for the summary of categories. Each interview began by asking participants to define "family" to establish their perspectives of the relationships in which growth might occur. All interviewees described family members as the "closest" people to an individual, regardless of genetics. Richard and Mark described family as being "anyone significant in that person's life" including "close friends". Care-coordinators were encouraged to think about whether their personal definition of family differed to their professional definition. Only two participants identified their personal definition of family as being more "close-knit" and "nuclear" than their professional definition. This could mean that for these two individuals, their perceptions of growth may be limited to those immediate relationships within the family, potentially neglecting the positive changes in the wider family system.

Care-coordinators spoke about growth and its emergence as being complex in its different facets and subtleties. For some cases, growth within the family was explicit and obvious to care-coordinators, but for others, growth was less identifiable to external observers.

2.1 Enhanced Communication

Seven care-coordinators described improvements in communication within families after they received input from the service. Families became more able to "speak the unspoken" and individuals were able to find their own voice and assert their personal needs.

2.1.1 Speaking the Unspoken

Care-coordinators described how their role encourages honest communication of difficult or negative topics that may have previously been unspoken within the family. Amy's client had been having nightmares about "hooded figures with the faces of family members". Once the client was encouraged to speak about these with family, they were able to make sense of her "hot and cold" interactions with them.

> *"So, when we've managed to talk about those nightmares and those links and tease a bit more out of it, which hadn't come out before, mum had said 'well that makes total sense now, that she wants to be comforted by us but she's frightened by us'."*
>
> *Amy*

Alice spoke about a conversation she had with one family where she highlighted how their wish to protect each other was preventing them from moving forward:

> *"I had a bit of a moment where I was like… 'you protect him from anything unpleasant, negative, dark, but actually he protects you and he didn't want to tell you what the voices were. He protects you from anything negative, unpleasant, dark.'…they don't tell each other the hard things… the difficult things."*
>
> *Alice*

Alice described how the client felt that psychosis had been a positive thing for him, due to the way in which the family could now communicate. It seemed that their improved communication allowed him to show his whole self to his family.

> *"…it kind of made him think 'I'm just going to pursue what I want' and he wanted to be a tattoo artist and he is. And it was having that communication with his family, who initially would have dismissed doing something so odd, were like 'right okay, how do we look into this, how do we explore it'."*
>
> *Alice*

This indicates that growth was not just about becoming more able to speak about psychosis experiences, but also about feeling more able to communicate difficult topics which, for this individual, was his choice of career.

2.1.2 Finding Voice

Kathryn's quote below, states how in moments of crisis, services can cause an individual's voice to feel lost. The rush to reduce risk reduces their ability to listen to their psychological needs. Despite this, three care-coordinators highlighted areas of individual growth where clients had been encouraged to find their own voice, which ultimately led to family growth due to enhanced understanding and communication of an individual’s needs. For one particular family, drama therapy supported a client with learning difficulties in finding his voice. The care-coordinator (Rob) described how this eased the parents’ concern that their son would not be able to cope without them, which incidentally, may have exacerbated the client’s worries about abandonment.

> *“I suppose when someone is in a crisis, I think that maybe acting quickly maybe means that it's not as therapeutic as it could be and why she might have felt like this about not feeling listened to because I suppose the priority was to ensure her safety and everyone else’s.”*
>
> *Kathryn*

> *“In the drama therapy….they experimented with not doing that [speaking for their son] and almost let the son take the reins a bit and he got bits of acting scenarios and things and he was able to control that situation and decide who did what and who said what kind of things… and both parents said that his confidence has as a result of this piece of work and the drama therapy… has really excelled to what I understand is a point beyond where it was before the episode.”*
>
> *Rob*

In this process of finding voice, clients were more able to assert their wants and needs. Richard’s client, who originally *“had a real passivity”,* became more able to voice his decisions for his future.

"He said 'I want to get a divorce I've not seen my wife for many years and I'm going to do that, I don't want to go to that church because it was too controlling, I like [West African country] but I don't want to live there, I want to get a job, I want to do my flat up'".

Richard

Care-coordinators spoke about this process being facilitated by formal and informal aspects of care such as drama therapy, family therapy or conversations with the care-coordinator. In addition to the three care-coordinators who spoke about finding voice, Sean described how family therapy enabled this opening up of communication within the family as a whole.

"It's almost like you know that the lid is off and "good yeah, now I can say all of this stuff". And then erm... and it's almost like permission to share those things that you have been thinking."

Sean

2.2 Less Explicit Constructs of Family Growth

Some care-coordinators found it difficult to identify growth if they perceived a lack of reduction of unusual experiences. When given the opportunity to reflect further on family stories, growth appeared in the form of distancing from unhelpful relational dynamics and setting new boundaries and norms.

2.2.1 Distancing from Unhelpful Relational Dynamics

Eight care-coordinators spoke about growth where family members felt more able to step away from relational dynamics that negatively impact their mental health. Amanda spoke about a client who made the decision to spend Christmas with his friends instead of his biological family.

> *"…as his journey has gone on, I guess [he] distanced himself from those relationships because they haven't felt that helpful and has kind of developed more support and closer relationships with other people who then he would see more as a family network."*
>
> *Amanda*

They spoke about families becoming more able to communicate their need space from each other.

> *"One of the most powerful tools that they developed was actually taking a step back and saying 'right I can't go over this accusation of an affair again… so I need to take a step back and I need to not see you at the minute until we can talk about something else'."*
>
> *Alice*

2.2.2 Setting New Norms and Boundaries

Six care-coordinators described how FEP encouraged families to set new boundaries and decide what is acceptable behaviour. Mark wondered whether to speak about one particular family as he initially perceived there to be no positive change. However, as he spoke he became aware of growth within the family, despite there not necessarily being improvement in the client's unusual experiences. The family he was working with had begun setting new boundaries.

"I think part of the journey for [client's] dad was that he managed to get to a place which he'd never been able to do before which was to say 'no'."

Mark

Mark stated psychosis caused an *"exacerbation"* of relational difficulties, without which a father may not have realised "*that he needed some sort of boundaries to protect himself*". This implies that growth in the form of boundary resetting may not have happened without the presence of FEP. Sean described how a family he had worked with had reset rules together.

"It was a resetting of these rules and what's okay."

Sean

One client learned to ask for the type of support that was most helpful for her, setting the boundary of whether she needs more or less care. The care-coordinator here implied that it was the influence of the service *"We"* that helped this family reset these boundaries.

"We [the service] managed to develop a really positive relationship where the client felt able to tell mum when she felt she was being a bit too much or when she was struggling and needed a bit of extra support and mum would offer some support that was helpful and not overwhelming."

Amanda

2. Prevention of Growth

Care-coordinators identified key factors that might prevent growth from occurring within families. They described how constructs of the "perfect family" and fear of being blamed may prevent acknowledgment and communication of family difficulties. They suggested that difficult relationships with the service may also limit family growth.

3.1 Family Construct of "perfect family model" and Fear of Blame

Four care-coordinators discussed the influence of the "perfect family" discourse and a fear of being blamed. Leanne spoke about the image of a perfect family, perpetuated by societal discourses within the media, preventing families from communicating their difficulties honestly with services.

" I go back to the media, I go back to social conditioning, look at the blooming oxo advert and you see these perfect perceived families all sitting round all thumbs up over a bit of gravy and you know… it's not always like that. And I think that probably families get anxious about professionals entering into their world. And… they may try to replicate that"

Leanne

Some families presented with fear of being blamed for the individual's unusual experiences. Sean described how some families find it easier to accept a biological diagnosis rather than a psychological difficulty that past trauma and difficult relational dynamics may have contributed to.

"Defences are up 'tell me that its biological, because then it's nothing that's happened in our fault that's made my son mad'."

Sean

The blame may be pushed onto the individual with unusual experiences and may lead to a breakdown in communication and acceptance of responsibility, and therefore a prevention of family growth.

"I think it's maybe the criticism that you hear, you know like the blame and things describing the person who has got the psychosis as having the problem. 'If they were well, then everything in the family would be fine'."

Michaela

3.2 Relationship with service

Nine care-coordinators described difficult relationships with the service as limiting family growth. Difficulties may arise as a result of mistrust in the service due to feeling let down by past services or clients' suspiciousness.

3.2.1 Negative Involvement with Services

It is common for clients to have had prior involvement with mental health or social services. Six care coordinators explained how previous negative experiences may prevent families from trusting the current service.

"I think sometimes as a mental health service you're put in this broad category of 'the services' or 'the institutions' so I think anyone that's had bad experiences of professionals or people in supposed helping professions or whatever, I think that you can be sort of tarred with the same brush understandably."

Rob

Michaela describes how this mistrust causes a lack of engagement, which may ultimately prevent exploration of difficulties that could lead to family growth.

> *"We've tried to encourage him to see us but he's not wanting to see us, so his engagement wasn't very good with our service, but then this is a person who probably feels deep down very let down by a lot of services from a young age and you know there is mega trust issues with professionals as well."*
>
> *Michaela*

3.2.2 Suspiciousness

Importantly, three care-coordinators mentioned that the client's unusual experiences and suspicious beliefs may impact their relationship with and trust in the service. These beliefs may partly be based on reality and past experience. Kathryn spoke about a client who had recently regained custody of her child. Her client believed that a vigilante group wanted to take her son away, which created great difficulty trusting the service and was perhaps perpetuated by her family member secretly contacting services. This limits open communication within the family unit, therefore, reducing the likelihood of experiencing family growth.

> *"It feels like she's really up against it, even maybe within the family. Maybe that's where some of this distrust [in the service] has come from. Just reflecting now… a very real fear of 'they're going to take my son away from me again', which has happened, and that then leading to some kind of hypervigilance about 'there's a set up', 'my phones been hacked and none of this is psychotic'."*

Kathryn

Alice described how a client's relationship with a care-coordinator may be influenced by their suspiciousness when exposed to an unfamiliar compassionate relationship.

"It's like trying to model this different type of relationship, and some people find that really difficult if they've never experienced it, a sort of compassionate understanding person can make people really suspicious."

Alice

Summary

From these themes, an initial theory can be developed that describes what family growth means to care coordinators working in EIP. There is an interesting parallel between the proposed model of growth and the experiences of positive and negative "symptoms" of psychosis. The addition of experiences, in this case communication (speaking the unspoken, and finding voice), is more overt and easier for care-coordinators to describe. Whereas the withdrawal of experiences, in this case distancing from unhelpful relationships and setting new boundaries, is less explicit and requires more in-depth reflection. This process is perhaps mediated by the EIP context, in which positive experiences may be spoken about most frequently, making the other aspects of growth less noticeable. Furthermore, care-coordinators attached themselves as contributory to the experiences of growth, however within the context of the EIP service did not consider their influence on the potential prevention of growth, instead they interpreted this as being related to the "perfect family" model and mistrust in the service as a result of prior experiences and suspiciousness.

Discussion

The findings suggest that care-coordinators witness growth within families when an individual is experiencing a FEP. Care-coordinators define “family” as those closest to an individual, however, some stated their personal definition as being more nuclear, consisting of immediate relatives. Perceptions of families are influenced by the care-coordinators’ personal experiences and their more “nuclear” lenses could prevent the witnessing of growth in the wider social network. It may influence who care-coordinators involve and invite to attend meetings.

Similar to Coldwell, Meddings and Camic (2011), enhanced communication skills were identified as an aspect of growth, where family members felt they need not hide negative thoughts or experiences as they became more trusting that the family could tolerate them. Communication was also extended to being able to discuss previously difficult topics, such as less traditional career choices. Individuals felt safer being authentic and showing their whole selves to their family. Erikson (1968) stated that authenticity is key for psychological growth; it is a necessary part of development enabled through a process of individuation. There is a sense of empowerment in individuals finding voice and becoming more able to express their needs. This may have felt personally enhancing, mirroring Coldwell, Meddings and Camic (2011) and Slade et al (2019) and seemed to be enabled by a process of reciprocal exchange.

Interestingly, findings suggested that some aspects of growth were less obvious to care-coordinators. Distancing from unhelpful relationships and boundary setting was perhaps less explicit as they occurred separately from recovery. Recovery is often thought of as the absence of symptoms, though services are encouraged to view recovery as a process of personal change towards life fulfillment (Harrison et al., 2001; Pitt et al., 2007). Care-coordinators were encouraged to reflect further on the experiences of families in order to identify and describe these aspects of growth. This may indicate the importance of regularly encouraging staff to think about family growth during supervision, to reaffirm that families may continue to grow despite residual unusual experiences. Future research may consider how discussions about growth could influence this process in families.

Distancing from unhelpful relationships reflects an individuation process (Erikson, 1968). Similar to Slade et al (2019), the experience of FEP and support provided by services meant that individuals had the opportunity to reflect on relationships that negatively impacted them. They felt able to discontinue these relationships, perhaps due to greater self-worth, discussed by Allman et al (2018). Additionally, setting new norms and boundaries was seen as an important part of family growth where the process of coping with and receiving support for FEP encouraged family members to become conscious of which behaviours or interactions made them unhappy, and what needed to change. Individuals recognised that the experience of FEP "exacerbated" relational difficulties and raised awareness of required boundaries. Growth appeared to present in the form of moving boundaries towards a more adaptive "clear" position, which Minuchin's (1974) structural family therapy theory identified as being neither too diffuse nor too rigid. This meant that family members may have felt more able to protect themselves from feeling exploited or intruded upon.

Care-coordinators described the experiences of growth as being prevented by two main themes: the family construct of the "perfect family" model, and the relationship with the service. The family construct of the "perfect family" model is portrayed within the media; in adverts, soaps and lifestyle magazines for example. The construct promotes a rhetoric whereby difficulties within relationships are viewed as abnormal and therefore shameful.

This stigma generates fear of seeking help and support, shutting down communication within the family and social network. Allman et al's (2018) study, where care-coordinators found it difficult to recruit individuals who they perceived to have positively contributed to their family, may reflect this process where it was more difficult to identify positivity in families that fell outside of societal norms. In this study, care-coordinators described the discourse as generating a fear of blame and therefore preventative of honest communication with professionals, which prevented open communication and overall family growth. Dixon et al (2018) described deficit driven literature around psychosis as contributory towards stigma that hinders personal growth. They proposed that a continuum model of experiences could help challenge the societal discourse that psychosis should be hidden.

Relationships with the service were potentially inhibitory of family growth. This emphasises the importance of having trust in the service, reflecting the principles of the Finnish open dialogue approach, whereby growth may be stunted if the relationship with the service isn't accounted for (Seikkula, Alakare & Aaltonen, 2001). The findings imply that families place mental health services into the same category as other social services such as the police, placing pressure on mental health services to repair the mistrust that may have been caused by other services, placing additional strain on the family-service relationships. This may slow a family's journey towards growth as they take more time to trust the service.

Furthermore, individuals' suspicious beliefs and/or unfamiliarity with compassionate relationships may prevent them from trusting EIP services. Their beliefs may be related to real-life experiences which emphasises the importance of sensitivity when developing a rapport with families. Similar to recommendations from Watkins, Sanderson and Richards (2018), care-coordinators should remain mindful of consistency and maintaining strict confidentiality and not talking to family members about the individual without their knowledge.

Limitations

The number of interviews were within the recommended sample for a grounded theory study, and participants were almost equally split between male and female. However, all participants were White British and therefore represented a very homogenous sample. Care-coordinators from different cultural backgrounds, or different services, may perceive the experiences of growth and families very differently, as the experience of psychosis itself is perceived differently in different cultures and different services. Therefore, perceptions are not representative of all care-coordinators and future research may consider gathering data from care-coordinators from different cultural backgrounds and from different EIP services.

Care-coordinators volunteered for the study if they were interested and could donate their time. Their interest in participating in the study could be because they felt they had more stories of growth that they wished to contribute and may be more optimistic members of the EIP team which may limit the generalisability of the findings. Care-coordinators were aware that the interviewer was a Trainee Clinical Psychologist which may have caused participants to adapt or filter responses to something they felt was more desired by the interviewer.

Finally, gathering the perceptions of family growth from care-coordinators may have made the experiences of growth distorted by the lens of both the care-coordinator and researcher. The described experience may be more removed and less accurate than had it been gathered from the family themselves. Future research may consider how the findings align with the perceptions of families. However, the care-coordinator perception is contributory and is of importance as their perceptions and appraisals influence how they work with families.

Implications

This is the first known paper that has considered staff perceptions of growth associated with a FEP. The study demonstrates that care-coordinators perceive growth to exist, mainly in the form of enhanced communication alongside distancing from unhelpful relationships and a setting of new norms and boundaries. Interviews revealed that there are less explicit forms of family growth that required further probing for care-coordinators to reflect on. This implies potential benefit in encouraging staff discussions around growth within families as separate to recovery, and as something that they may well have contributed towards.

The research emphasises the relevance of an open dialogical process between individuals with FEP, families and staff, to encourage open conversation that promotes empowerment and authenticity. It highlights the importance of challenging the family construct of the "perfect family" model, by normalising and de-shaming psychosis experiences and relational difficulties, to encourage necessary help-seeking within families. Establishing trust between families and services is key and should be considered a priority when working with families with FEP, where services consider the family's prior interactions with services as well as suspicious beliefs that could be reinforced by communications between the service and family.

Conclusions

Overall, care-coordinators perceive the existence of family growth associated with a FEP. The key aspects of growth are enhanced communication, distancing from unhelpful relational dynamics and a re-establishment of norms and boundaries. This growth is inhibited the “perfect family” discourse and mistrust in services, preventing help-seeking and engagement, which consequently prevents honest exploration of difficulties. Results reinforce the importance of family involvement in EIP where open communication is encouraged; it is this that encourages the process of growth within families.

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Part Three: Appendices

Appendix A: Reflective statement

Conducting this research and writing this thesis has been a journey of many ups and downs. Often, I have felt like I was taking two steps forwards and one step back. I was moving forwards, but very slowly. My desire to be a perfect researcher, conduct perfect interviews and write a perfect paper has been constantly tested and led me to the ultimate conclusion that my best is as perfect as it gets, and that perfection is a construct that doesn't really exist.

Firstly, it is important to reflect on the context in which the majority of this thesis was written, amongst a global pandemic where nothing felt more important than the health of my loved ones. I was not allowed to be physically close to my family, yet we remained emotionally close and, in some ways, more connected. I am now more aware than ever of the potential for growth following all types of adversity. Although, I am fortunate and have the privilege of being raised in a close family, where open and honest communication is practiced, despite any potential discomfort. This means that the lens through which I see families and relationships with early psychosis, is shaped by a narrative where individuals are securely nurtured and supported within the confines of their family system. Of course, this is not the case for all families and therefore it is a bias that I have had to be constantly aware of.

I was first introduced to the idea of the psychosis continuum by one of my supervisors for this thesis. We explored the notion of unusual experiences becoming problematic when an individual finds them distressing. I recalled times during my childhood where I would watch mediums or ghost hunters describe their beliefs about the paranormal world and wondered whether these individuals would be deemed as "psychotic" if they became distressed or overwhelmed by their experiences. This interest in paranormal psychology and the psychosis continuum then led me to the idea of growth; positive change became the focus instead of burden, fear and distress. The concept of family growth resonated with me after I had experienced this within my own family system after a close family member had become unwell. I reflected on the initial anguish that was followed by a strengthening within family relationships and a sense of re-established perspective of the world and what it means to be alive.

I hoped to learn more about growth within families, but in order to add something new to the current literature, this had to be done through the lens of care-coordinators. This meant that the experiences of families were being focused on through two sets of lenses: mine and care-coordinators. This again, aggravated my perfectionism, as I worried that the findings might feel far away from the truth. However, the social-constructivist stance alleviated these perfectionistic concerns, as it appreciated that generating new meaning from the research was always going to be a co-construction and that this was good enough.

I learnt through the process of conducting interviews with care-coordinators, that interviews wouldn't always be perfect. Since humans are extremely complex beings with their own agendas and needs, the "perfect interview" according to qualitative research books, was not always possible. Likewise, perfect memo writing, and data analysis was also impossible. I gradually let go of perfectionism after reading Charmaz's (2014) book on constructing grounded theory where she stated that memos are idiosyncratic to the researcher. My memos and initial data analyses made sense to me and therefore provided a good basis for beginning the full data analysis. During my final analyses, I found it most difficult to let go of poignant quotes, which although not strictly related to family growth, still felt meaningful and important. My supervisor reminded me on two occasions that I had done my interviewees honour and justice already, by listening to them in the first place, and that including everything was not realistic for this current paper. On reflection, I think this is true; many of the interviewees expressed a sense of pleasure in being given the opportunity to reflect on family stories and growth. I am glad that I could give this time to care-coordinators.

In writing the systematic literature review, I felt in some ways closer to the experiences that families go through. The literature review became my "safe base", where I found certainty and security in the piece of work as data collection and data analyses did not change in the way that my constructivist grounded theory empirical study did. I found enjoyment in reading the literature and felt like a detective as I delved into the literature to find specific quotes describing changes in relationships. Synthesising the data and developing a narrative around how family relationships might change when psychosis is present was incredibly interesting and hopeful to see the positive changes that individuals described.

Overall, the process of conducting research and writing this thesis has been arduous but extremely rewarding. My overall aim was to show families who may experience psychosis, that the experience need not be one consumed by fear, but one that may encourage families and relationships to grow and thrive. I feel that the journey of families, in some way reflects my own personal research journey. I initially felt rather overwhelmed and fearful of my own high expectations, but in time became more accepting of when I was "good enough". This, for me, has been an experience from which I have grown and will carry forward into my career and personal life.

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Appendix B: Epistemological statement

Alignment of epistemological stances and data analysis methods is important for researchers; it places them in better stead to engage with and continuously reflect on their research (Bracken, 2010). This epistemological statement describes the stance in which the researcher adopts, and explores it's influence on this thesis.

Psychology has largely taken a positivist stance where theory is both a prediction and an explanation, and truth is objective and confirmed by cause-effect linkages (Lincoln, Lynham and Guba, 2011). However, this thesis utilised dialogical methods, in which subjective findings were synthesised between the interviewees and the interviewer. The findings were a co-construction of truth, based on consensus amongst participants, that was influenced by sociocultural and constructed concepts such as time, culture and religion. Therefore, a social constructivist epistemological stance and an ontological position of relativism was taken by the researcher.

The researcher considered the construction of psychosis within society in the United Kingdom. General discourses often suggest the relation between mental illnesses and violence. Monahan (1992) described how this discourse has an ominous impact on patient advocacy, treatment and policy setting for individuals who have diagnoses such as psychosis. These discourses and this use of language creates a concept that society deems to be true. This perceived "truth" is powerful in that it may lead to a self-fulfilling prophecy, which Merton (1948) described as a social process whereby peoples' interpretations have the power to influence behaviour.

This influence of interpretation and language meant that the researcher was strict in acknowledging the potential power that her interpretations of data may have on those who read the paper. Acknowledging the influence of language and interpretation was vital throughout the research process since the grounded theory approach to coding and data analysis is very interpretative in nature. Indeed, these interpretations are likely influenced by the researcher's context, as well as reading of prior theories and literature. A stance of theoretical agnosticism advocates for analysis of prior reading rather than denying its existence (Henwood & Pidgeon, 2003).

Grounded theory was identified as being most appropriate for the current research, not just because it aligns with the researcher's perception of truth, but because it addresses "why questions", such as "why might family growth associated with psychosis be prevented?". The researcher had constant iterative interactions with the data where categories were derived from interpretations that the researcher had made. Charmaz (2012) identified that codes and categories are derived from what "strikes" the researcher as important, and the constructivist approach recognises that this depends on the 'lens' of the individual researcher.

Overall, the social constructivist epistemological stance was adopted throughout the process where close attention was paid to the use of language, meanings and interpretations. The final findings are recognised as being a co-construction and consensus of ideas that are influenced by the lenses of both the researcher and participants.

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Appendix C: Submission guidelines for Psychosis journal

Preparing Your Paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

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).

Word Limits

Please include a word count for your paper.

The maximum word length for an Article in this journal is 6000 words (this limit includes tables, references and figure captions).

The maximum word length for a First Person Account is 3500 words.

The maximum word length for a Brief Report is 1500 words.

The maximum word length for an Opinion Piece is 1500 words.

The maximum word length for Letters to Editor is 400 words.

The maximum word length for a Book Review is 1000 words.

Style Guidelines

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use double quotation marks, except where “a quotation is ‘within’ a quotation”. Please note that long quotations should be indented without quotation marks.

Formatting and Templates

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

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Checklist: What to Include

1. **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICMJE) requirements for authorship is included as an author of your paper. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). 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.
3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. Between 5 and 6 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:

   For single agency grants

This work was supported by the [Funding Agency] under Grant [number xxxx].

For multiple agency grants

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].

6. **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.
7. **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.
8. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
9. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
10. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are

acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.

11. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
12. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
13. **Units.** Please use SI units (non-italicized).

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Disclosure Statement

Please include a disclosure statement, using the subheading "Disclosure of interest." If you have no interests to declare, please state this (suggested wording: *The authors report no conflict of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the declaration of interest statement. Read more on declaring conflicts of interest.

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All authors are required to follow the ICMJE requirements on privacy and informed consent from patients and study participants. Please confirm that any patient, service user, or participant (or that person’s parent or legal guardian) in any research, experiment, or clinical trial described in your paper has given written consent to the inclusion of material pertaining to themselves, that they acknowledge that they cannot be identified via the paper; and that you have fully anonymized them. Where someone is deceased, please ensure you have written consent from the family or estate. Authors may use this Patient Consent Form, which should be completed, saved, and sent to the journal if requested.

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Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

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Appendix D: Quality Assessment 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:	Clearly described Unclear Not described	Comments:

• 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?		
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?	Rigorous Not rigorous Not sure/not reported	Comments:

• Is it clear how the themes and concepts were derived from the data?		
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?	Convincing Not convincing Not sure	Comments:

- Are the data appropriately referenced? - Is the reporting clear and coherent?		
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?	Appropriate Inappropriate Not sure/not reported	Comments:

• 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?		
Overall assessment		
As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)	++ + −	Comments:

Appendix E: Quality assessment scores of reviewed papers

Research Paper	Checklist Item														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Score
Newman, Simonds & Billings (2011)	Appropriate	Clear	Defensible	Appropriately	Not Described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Wainwright, Glentworth, Haddock, Bentley, Lobban (2015)	Appropriate	Clear	Defensible	Appropriately	Unclear	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
McCann, Lubman & Clark (2011)	Appropriate	Clear	Defensible	Appropriately	Not Described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Sin, Moone, Harris, Scully & Wellman (2012)	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++
Onwumere, Parkyn, Learmonth &	Appropriate	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++

Kuipers (2019)															
Hickman, Newton, Fenton, Thompson, Boden & Larkin (2016)	Appropriate	Clear	Defensible	Appropriately	Clearly described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	Appropriate	++

Appendix F: Participant information sheet

INFORMATION SHEET FOR PARTICIPANTS

Title of study: Care-coordinators' perceptions of family growth associated with a first episode of psychosis

I would like to invite you to participate in a research project, which forms part of my doctorate research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

We know very little about the positive changes in families when a relative has experienced a first episode of psychosis and we know even less about how staff perceive this growth. This study is looking to explore what care-coordinators notice in families when an individual has experienced psychosis. We hope that this study will help us to understand whether any positive changes within families are noticed and how we might encourage these in the future.

Why have I been invited to take part?

You are being invited to participate in this study because you have expressed interest. You are a care-coordinator who has worked closely with individuals with psychosis and their families.

What will happen if I take part?

If you agree to take part, please complete a form with your contact details and another form with your demographic information and give these to the researcher (Emily Thornhill) or Chris Sanderson (Clinical Psychologist). I will contact you to arrange a meeting at your work place at a convenient time for you. You will have a conversation with me which will last around 60 minutes. I will ask you about your experience of positive changes in families when an individual has experienced first episode psychosis. I will audio record the discussion. There are no right or wrong answers and I am only interested in your opinions, your beliefs and your experience of working with individuals with psychosis and their families.

It is possible that you may be invited to attend a follow-up interview in order to discuss your experiences and opinions in more depth. You are not obligated to attend a further interview and one interview is likely to be sufficient.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact me if you have any questions that will help you make a decision about taking part. If you decide to take part, I will ask you to sign a consent form and you will be given a copy of this consent form to keep.

What are the possible risks of taking part?

Participating in the study will require 60 minutes of your time and this may be inconvenient for you. Some people may find it upsetting when talking about working with families with psychosis because it may bring to mind difficult issues about psychosis or working with families in general. If this happens to you, the researcher will offer support and help you to gain access to further support from your clinical supervisors.

What are the possible benefits of taking part?

We cannot promise that you will have any direct benefits from taking part in the study. However, it is hoped that the information you give us will help us to understand more about families living with psychosis. It may also help to improve service delivery. Sometimes, staff members find it useful to have the opportunity to talk about their experiences of working with clients and their families.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR).

All of the personal information that you provide will be kept strictly confidential and anonymous. Any information that could be used to identify you will not be used in the research. Direct quotes from the discussion may be used in research publications and presentations but you will not be identified in these. To protect your anonymity you will be assigned a code or pseudonym. This will ensure it will not be possible to identify you from the information you provide. To protect the security of the audio recordings an encrypted recording device will be used. After the research is completed, all of the audio recordings will be destroyed. Anonymised transcripts of the recordings will be stored securely in an on-line storage repository at the University of Hull for a period of ten years. The only time that information cannot be kept confidential is if you disclose something that suggests that you or someone else is at risk of serious harm. If this happens during the interview, the researcher will need to contact appropriate authorities to ensure that you and other people are safe. The researcher will try to discuss this with you before any action is taken

Your contact details will be held securely for the duration of the research but then destroyed when the research is complete.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a ‘task in the public interest’ You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you**.** Information about how the

University of Hull processes your data can be found in the Research Privacy notice which will be given to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Hull Information Compliance Manager, Mr Luke Thompson (l.thompson3@hull.ac.uk). If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What if I change my mind about taking part?

You are free to withdraw at any point of the interview, without having to give a reason. Withdrawing from the interview will not affect you in any way.

You are able to withdraw your data from the study up until transcription has commenced, after which withdrawal of your data will no longer be possible as the data will have been anonymised and/or committed to the final report. If you choose to withdraw from the study before this point, the data collected will be destroyed.

What will happen to the results of the study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk/ The research may also be published in academic journals or presented at conferences.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Emily Thornhill
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07739436850
E-mail: E.thornhill@2017.hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the research supervisors' details below for further advice and information:

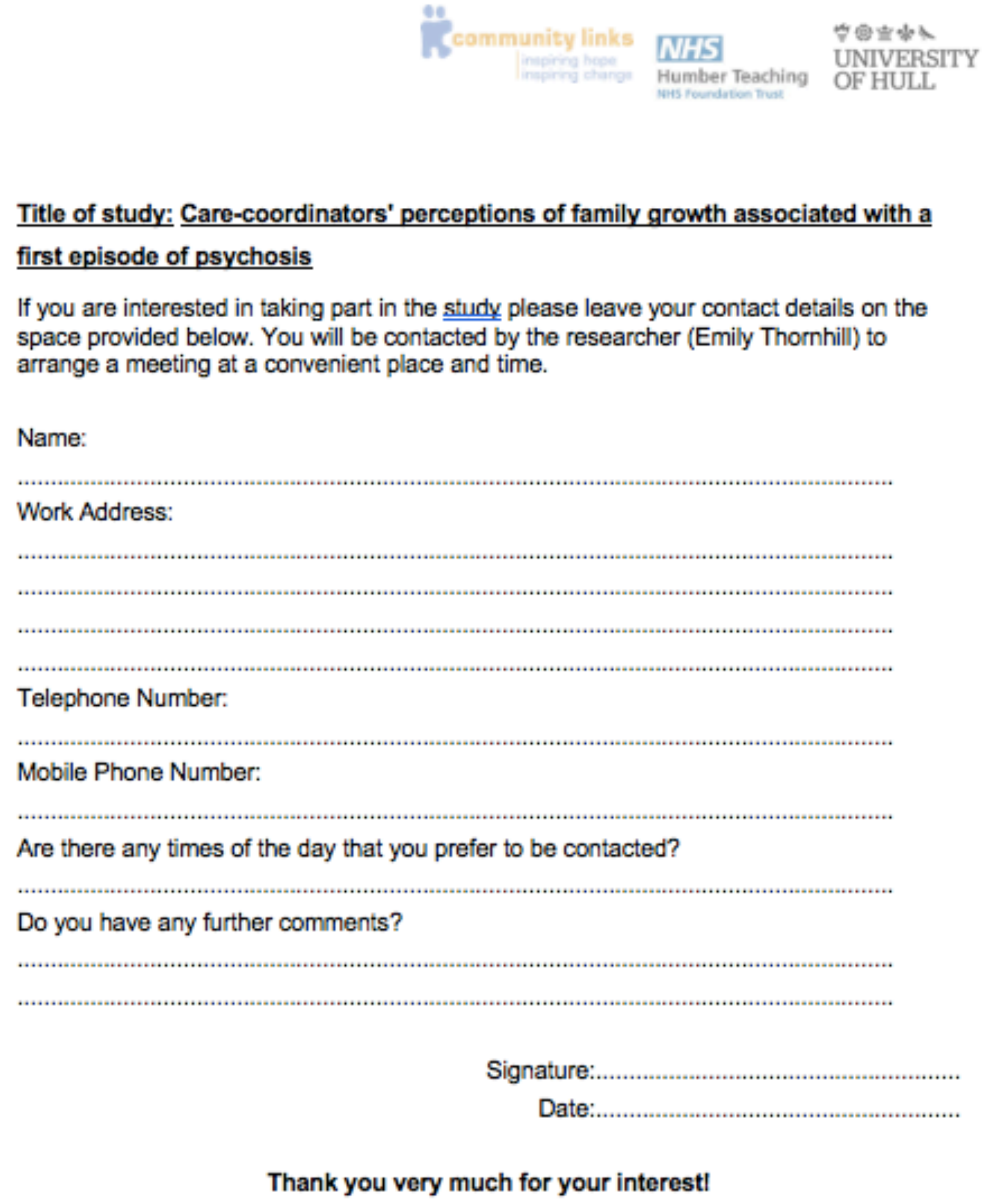
Dr Chris Sanderson **Dr Anjula Gupta**

Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07852134817
Email address: c.sanderson@hull.ac.uk

Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 01482 464087
Email address:
a.gupta@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix G: Participant contact slip



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inspiring change

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Humber Teaching
NHS Foundation Trust

UNIVERSITY
OF HULL

Title of study: Care-coordinators' perceptions of family growth associated with a first episode of psychosis

If you are interested in taking part in the study please leave your contact details on the space provided below. You will be contacted by the researcher (Emily Thornhill) to arrange a meeting at a convenient place and time.

Name:

....

Work Address:

....

....

....

....

Telephone Number:

....

Mobile Phone Number:

....

Are there any times of the day that you prefer to be contacted?

....

Do you have any further comments?

....

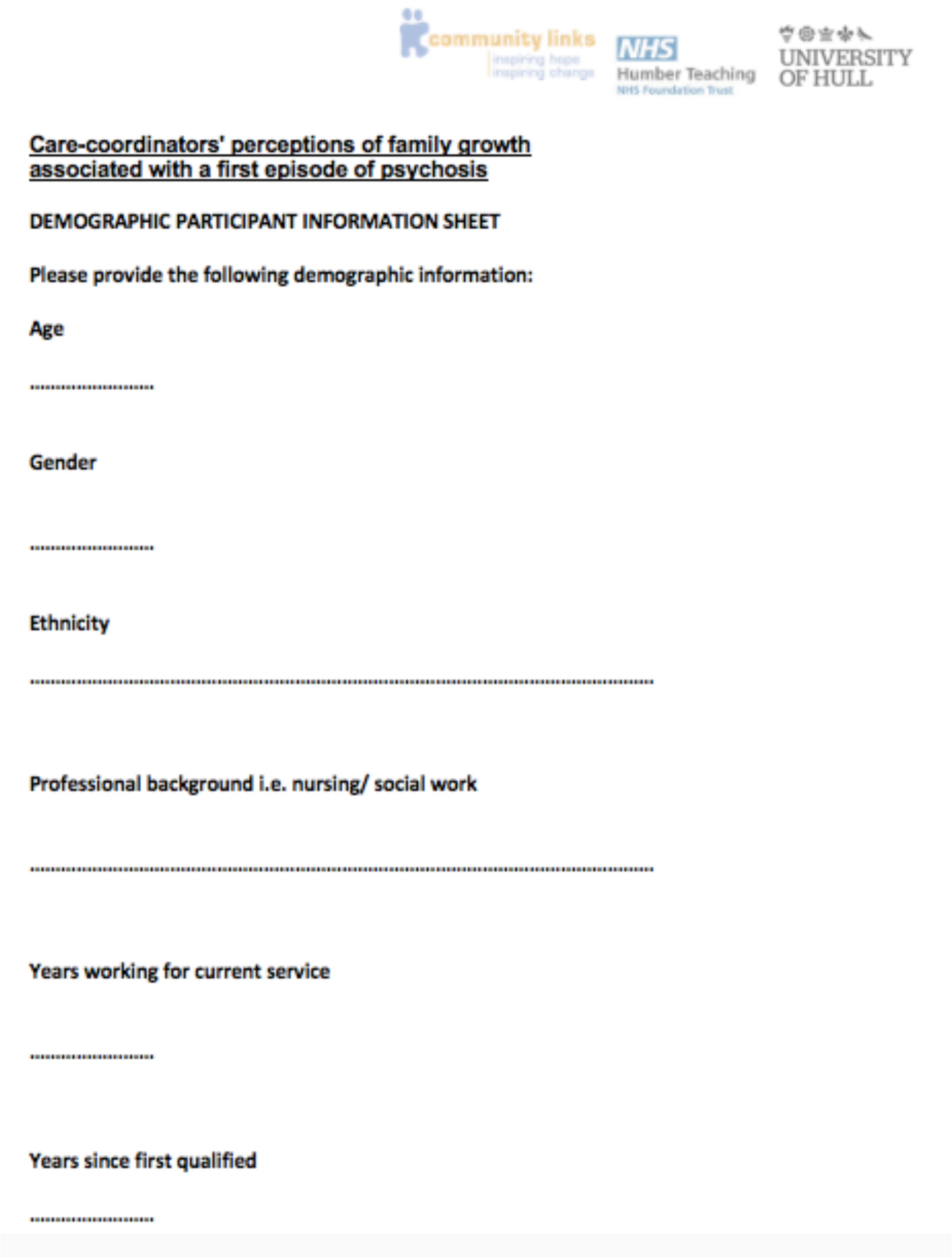
....

Signature:..

Date:..

Thank you very much for your interest!

Appendix H: Participant demographic information sheet



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Care-coordinators' perceptions of family growth associated with a first episode of psychosis

DEMOGRAPHIC PARTICIPANT INFORMATION SHEET

Please provide the following demographic information:

Age

………………………

Gender

………………………

Ethnicity

……

Professional background i.e. nursing/ social work

……

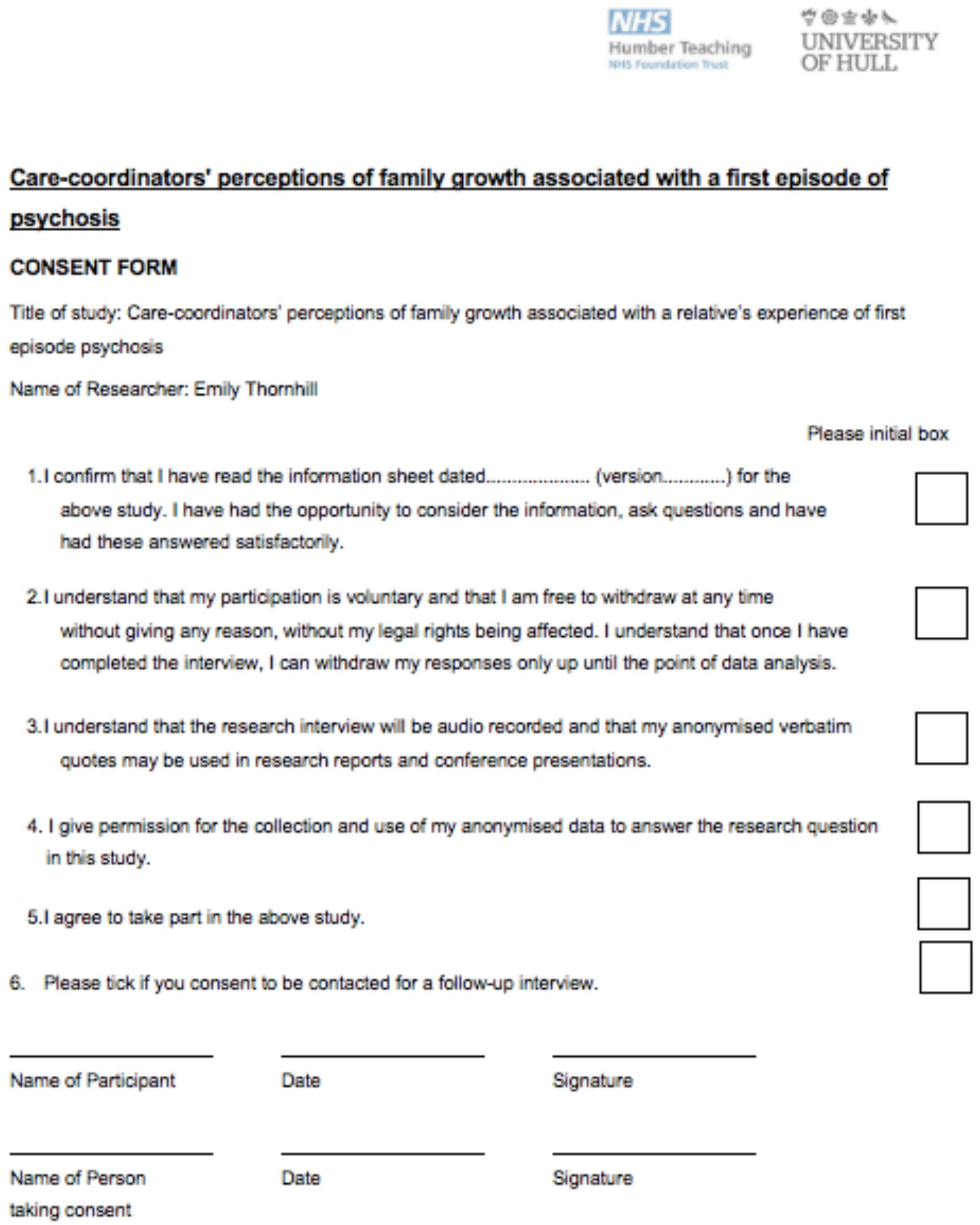
Years working for current service

………………………

Years since first qualified

………………………

Appendix I: Participant consent form



NHS Humber Teaching NHS Foundation Trust

UNIVERSITY OF HULL

Care-coordinators' perceptions of family growth associated with a first episode of psychosis

CONSENT FORM

Title of study: Care-coordinators' perceptions of family growth associated with a relative's experience of first episode psychosis

Name of Researcher: Emily Thornhill

Please initial box

1. I confirm that I have read the information sheet dated.................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. I understand that once I have completed the interview, I can withdraw my responses only up until the point of data analysis. ☐
3. I understand that the research interview will be audio recorded and that my anonymised verbatim quotes may be used in research reports and conference presentations. ☐
4. I give permission for the collection and use of my anonymised data to answer the research question in this study. ☐
5. I agree to take part in the above study. ☐
6. Please tick if you consent to be contacted for a follow-up interview. ☐

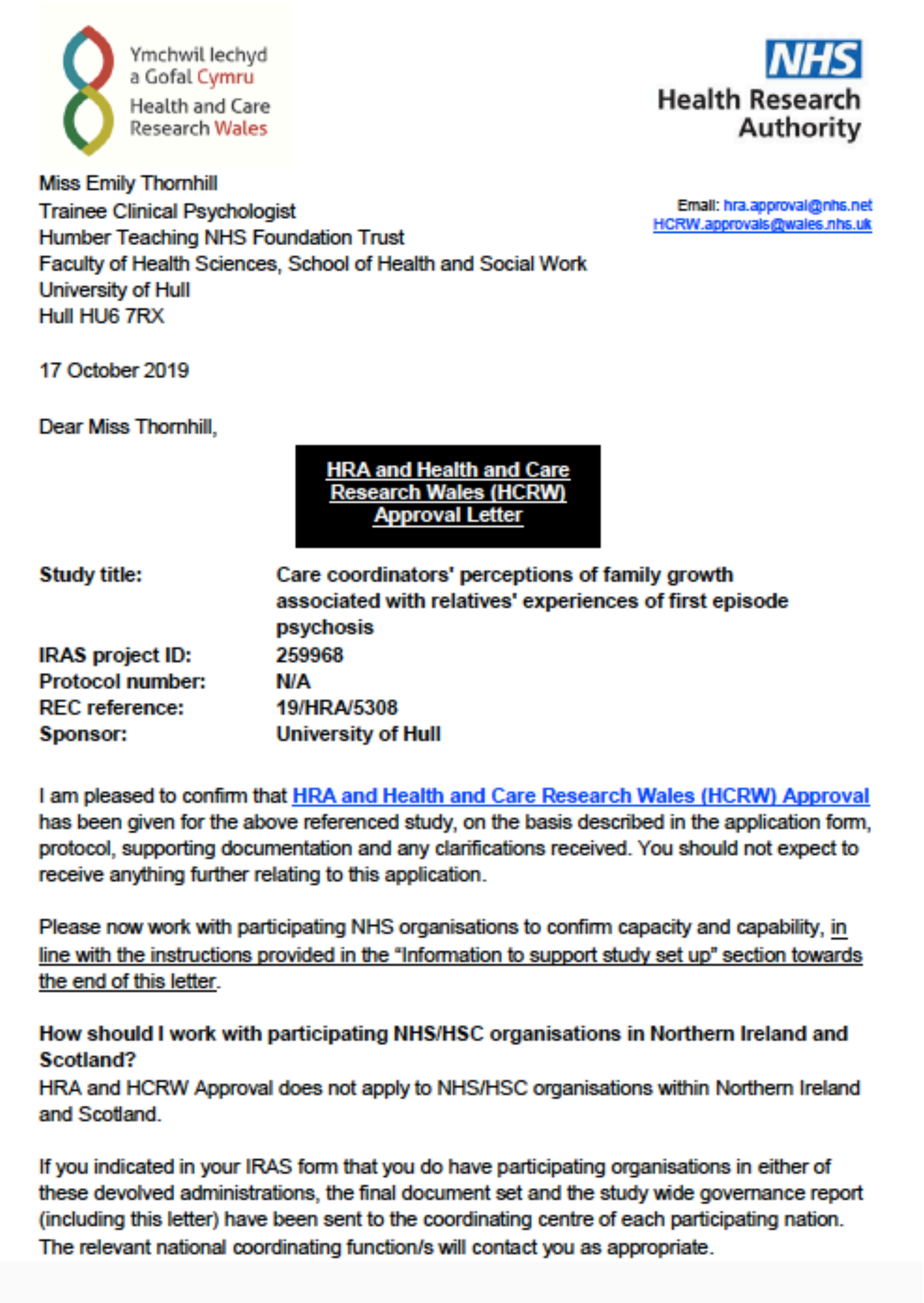
Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix J: Interview guide

Interview guide

Participants will be asked key questions; What is your experience of working with families living with psychosis? What changes have you noticed within families that have experienced a family member with psychosis? How do you think psychosis as an experience may have caused these changes within the family? As stated in Charmaz (2014) The interview will pay attention to language and discourse in order to explore the meanings within the data and explore how they might define the concept of “family growth”, in an attempt to gain insight into their assumptions and implicit beliefs. Similarly to Roger’s (1951) non-directive client-centred therapy the interviewer will reflect back some of the interviewee’s responses as an open ended question in an aim to illicit further depth throughout the inquiry.

Appendix K: Ethical approval documentation



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

Miss Emily Thornhill
Trainee Clinical Psychologist
Humber Teaching NHS Foundation Trust
Faculty of Health Sciences, School of Health and Social Work
University of Hull
Hull HU6 7RX

17 October 2019

Dear Miss Thornhill,

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Care coordinators' perceptions of family growth associated with relatives' experiences of first episode psychosis**
IRAS project ID:	**259968**
Protocol number:	**N/A**
REC reference:	**19/HRA/5308**
Sponsor:	**University of Hull**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The "*After HRA Approval – guidance for sponsors and investigators*" document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

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

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

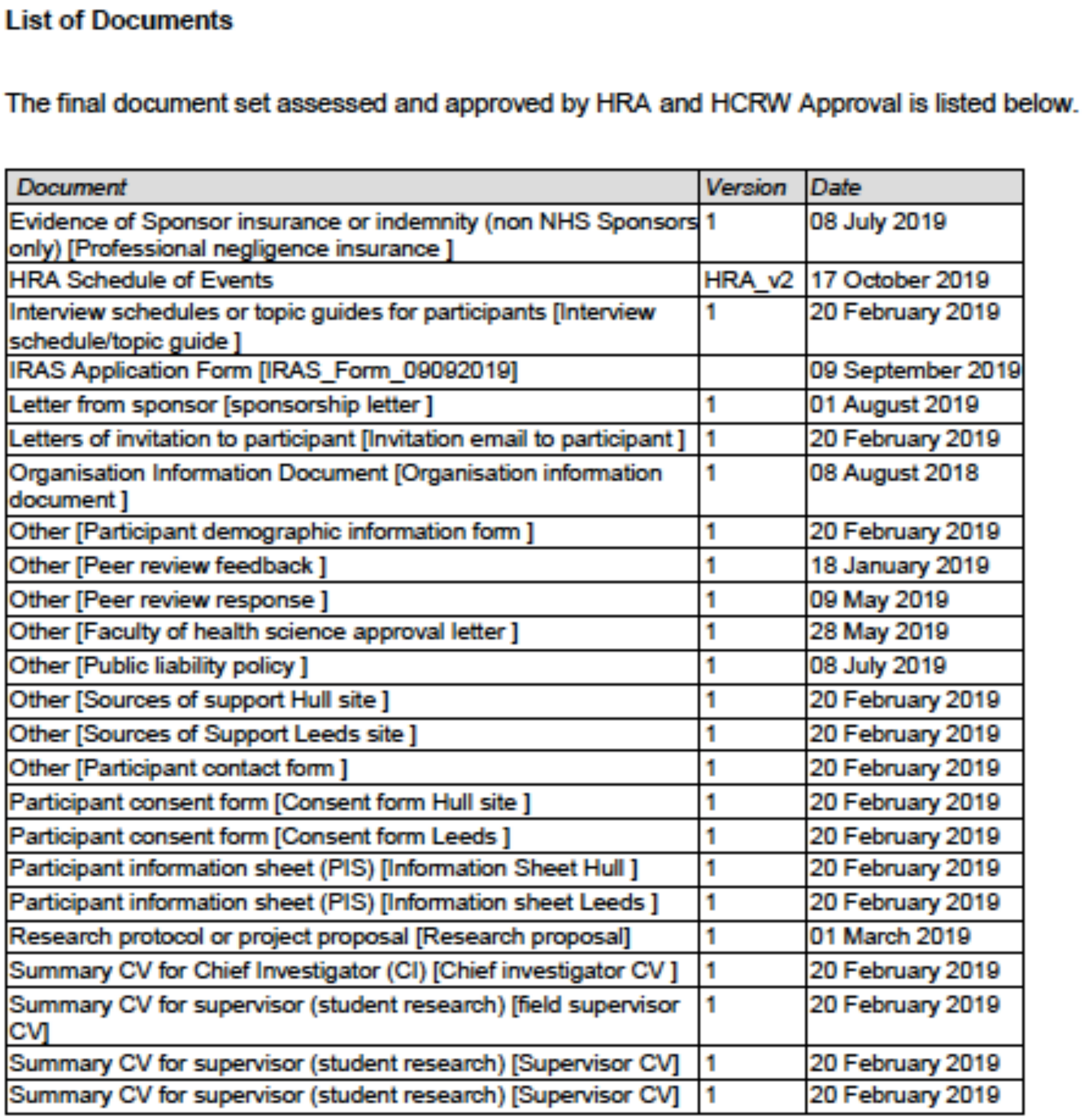
Your IRAS project ID is **259968**. Please quote this on all correspondence.

Yours sincerely,

Emma Stoica
Approvals Manager

Email: hra.approval@nhs.net

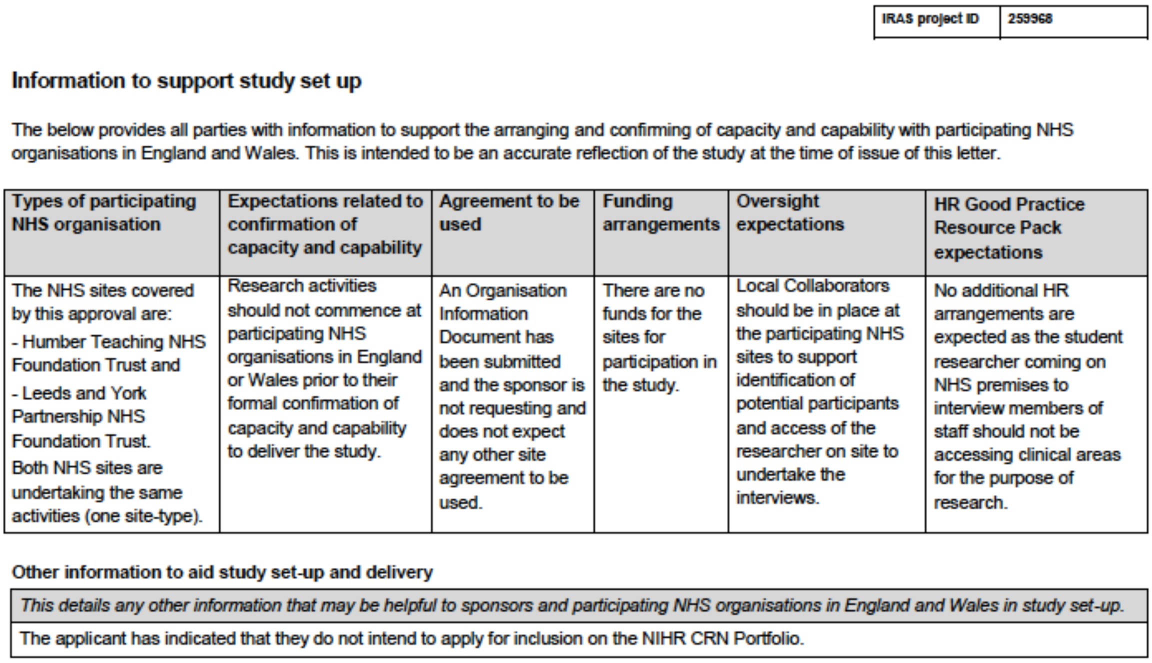
Copy to: *Dr Andrew Taylor*



List of Documents

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

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional negligence insurance]	1	08 July 2019
HRA Schedule of Events	HRA_v2	17 October 2019
Interview schedules or topic guides for participants [Interview schedule/topic guide]	1	20 February 2019
IRAS Application Form [IRAS_Form_09092019]		09 September 2019
Letter from sponsor [sponsorship letter]	1	01 August 2019
Letters of invitation to participant [Invitation email to participant]	1	20 February 2019
Organisation Information Document [Organisation information document]	1	08 August 2018
Other [Participant demographic information form]	1	20 February 2019
Other [Peer review feedback]	1	18 January 2019
Other [Peer review response]	1	09 May 2019
Other [Faculty of health science approval letter]	1	28 May 2019
Other [Public liability policy]	1	08 July 2019
Other [Sources of support Hull site]	1	20 February 2019
Other [Sources of Support Leeds site]	1	20 February 2019
Other [Participant contact form]	1	20 February 2019
Participant consent form [Consent form Hull site]	1	20 February 2019
Participant consent form [Consent form Leeds]	1	20 February 2019
Participant information sheet (PIS) [Information Sheet Hull]	1	20 February 2019
Participant information sheet (PIS) [Information sheet Leeds]	1	20 February 2019
Research protocol or project proposal [Research proposal]	1	01 March 2019
Summary CV for Chief Investigator (CI) [Chief investigator CV]	1	20 February 2019
Summary CV for supervisor (student research) [field supervisor CV]	1	20 February 2019
Summary CV for supervisor (student research) [Supervisor CV]	1	20 February 2019
Summary CV for supervisor (student research) [Supervisor CV]	1	20 February 2019



IRAS project ID	259968

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
The NHS sites covered by this approval are: - Humber Teaching NHS Foundation Trust and - Leeds and York Partnership NHS Foundation Trust. Both NHS sites are undertaking the same activities (one site-type).	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	There are no funds for the sites for participation in the study.	Local Collaborators should be in place at the participating NHS sites to support identification of potential participants and access of the researcher on site to undertake the interviews.	No additional HR arrangements are expected as the student researcher coming on NHS premises to interview members of staff should not be accessing clinical areas for the purpose of research.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix L: Example of data analysis

Transcript	**Initial Coding**	**Initial Categories**
Sean: Erm… I am trying to think of the different families that I have worked with. They're just really different. Really different. So, the biggest key is I have never seen it not… or should I say every single… but every time I have worked with a family	Differences in experiences working with families.	Family differences
before I have seen communication within the family increase, erm… and that can be a good thing and sometimes it ha taken them a	Increase in communication	Enhanced communication
long time to get there. But by the time I have kind of finished that seems to be the kind of theme like throughout. And like I say	Long process towards increasing communication within families.	Enhanced communication
sometimes that's got a rougher start because this might be the first time that really huge issues have been talked about openly erm… and then obviously, I'm thinking abut some of the different families like, it kind	Difficulties in opening up huge issues towards the beginning of receiving support from service.	Initial challenge in opening up
of brings up conversations that actually is nothing particularly to do with the reason that we are there, but it just kind of naturally leads into other discussions about maybe other family issues or other situations that's happened and it kind of all of a sudden… for the first time there is a space to discuss that. Erm… I am thinking of one family in particular who had a family intervention.. and quite a lot of the family therapy sessions was not about the client and the psychosis that they were going for but the makeup of the family, how they have got to the situation that they are. And that conversation revolves around things that happened, yeah… 10 plus years ago. Because for the first time we were in a situation that felt	Service as providing a space where previously unsaid things, not necessarily to do with psychosis, can be said.	Enhanced communication
okay to discuss that stuff. Interviewer: So, when… I think what you are saying is that you found. and you have seen in multiple families that communication has got better between family members. **Sean:** Yeah sure.	Safety in talking about early events when supported by team	Safety in opening communication

Interviewer: When you say communication, what do you mean by that?		
Sean: Erm…*laughs*… what's the phrase that Adam uses? Erm… he's got a really good term of phrase for it. But essentially its bringing what we think and taking it to what we say…because the same situation can go over and over and over and you know someone internally thinks "I'm unhappy with this" "I wish I could say this" or it might not even be those types of thoughts it might just be a feeling of unhappiness or sadness but giving a space to share those things and the amount of things that	Communication as saying what is being thought	Speaking the unsaid
someone comes back with "I had no idea you felt like that" and "I have no idea that was making you feel like this" and "I had no idea that made you think this" and "I dint know you thought that about me" because again its to have that space to be free, to be okay, to be certain. And it's like… it, I mean, it's that old thing like having a	Communication, when supported by service, allowing family members to realise how their relative has been feeling.	Enhanced communication
professional in the room kind of keeps a lid on things. Like whereas it might have gone really volatile or maybe someone would have left the conversation or it just kind of makes everyone… I think this is the case not just for therapy but just for any kind of session… kind of engage them a little bit more	Mental health professional can contain the family and helping to prevent a volatile atmosphere.	Containment provided by service
and probably active listen a little bit more as well. When someone is talking about you in a session room, it's kind of like okay then let's see what you have got to say then and you are maybe thinking like "ah I don't want to listen to what you have got to say, I'm going to leave..." so I think that always helps.	Sessions help individuals to learn to actively listen to family members.	Sessions encouraging enhanced communication