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Exploring the experiences and understandings of psychosis through relationships with

family members, mental health services, and society

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Word Count Statement

Thesis section	Text	Tables, figures, and references	Appendices	Total
Abstracts				580
Thesis	283			
Literature Review	149			
Empirical Paper	148			
Literature Review	9524	4194	3787	17505
Empirical Paper	10350	2174	5023	17547
Critical Appraisal	3774	479	-	4253
Ethics Section	5351	-	3121	8472
Totals	29579	6847	11931	48357

Abstract

This thesis includes three sections: a literature review, an empirical paper, and a critical appraisal of the thesis.

Early Intervention Services (EIS) are specialist mental health services for people who are experiencing a 'first episode of psychosis'. EIS are a widely adopted approach in England and internationally. Previous qualitative research exploring people's experiences of accessing EIS was reviewed through a process of meta-ethnography. Eleven qualitative articles were included in this review; the findings of these studies were analysed and synthesised. Four major themes were developed: Understanding through relationships; Recovery and hope; Sense of self; and Medication. Recommendations for clinical practice and future research were made.

There is a widespread narrative in most Westernised societies that mental health difficulties 'run in families'. One account of this attributes familial mental health difficulties to environmental or psychosocial factors, the other leading account links mental health difficulties to biogenetic factors. This study was interested in how these two accounts impact on people who have a parent with experiences of mental health difficulties. I interviewed four people who had a biological parent with experiences of 'psychosis' or a diagnosis of 'schizophrenia'. The interviews were analysed using Interpretative Phenomenological Analysis. Four super-ordinate themes were developed: The Fear; Signs of (in)sanity - navigating my own mental health; 'Who is my mum?' - multiple and evolving identities, relationships, and (re)connection; (4) 'A caregiver for your caregiver' - multiple family roles and responsibilities. Clinical and research implications were discussed.

The critical appraisal explored: my own inspirations for conducting the empirical paper; how the empirical paper influenced my own practice; and controversies and issues surrounding the biomedical model and its impact on families. Methodological challenges associated with this research were also discussed.

Declaration

This thesis records the work undertaken for the Doctorate in Clinical Psychology at Lancaster University's Division of Health Research. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a degree elsewhere. The authors have no competing interests to report.

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Section One: Literature Review

Individuals' experiences of accessing Early Intervention Services:

A meta-ethnography

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Abstract

Early Interventions Services (EIS) are internationally adopted, specialist mental health services for people who are experiencing a 'first episode of psychosis'. Although quantitative research is important in demonstrating the effectiveness of EIS, it is also important to understand how people who access these services, sometimes referred to as 'service users', experience EIS. This meta-ethnography synthesised previous qualitative research looking at people's experiences of accessing EIS. Eleven articles were retrieved from database searches and analysed. Four main themes were developed through this process: (1) Understanding through relationships, (2) Recovery and hope, (3) Sense of self, (4) Medication. A 'third-order synthesis' was developed, providing a conceptual map of an individual's journey into, through, and out of an EIS. Implications for clinical practice were made, such as EIS staff incorporating personal beliefs into shared understandings of 'psychosis', emphasising shared decision making, and addressing stigma. Recommendations for future research were also made.

Keywords: meta-synthesis, meta-ethnography, early intervention, service user

Over the past two decades, providing timely access to specialist mental health services for individuals who experience 'psychosis' has become a focal point of healthcare policy both in the United Kingdom (UK) and internationally (Department of Health and Long-Term Care, 2011; NHS England, 2016; Orygen, 2016). These specialist services come under different names but are often referred to as Early Intervention (EI) services in the UK. The concept of EI services (EIS) emerged from research in the 1990's which presented the 'critical period hypothesis of psychosis' (Birchwood, Todd, & Jackson, 1998). This suggests that there is a critical time window (two to three years) following a person experiencing a 'first episode of psychosis' during which, if appropriate 'treatment' is offered, the chances of recovery are increased (Birchwood & Fiorillo, 2000). The EI approach is now the predominant model within the National Health Service (NHS) and is the recommended 'treatment' option in England (National Institute for Health and Care Excellence [NICE], 2011) and internationally (International Early Psychosis Association, 2005). Typically, EIS are community-based, multidisciplinary teams which offer evidence-based interventions and support for people who have experienced (or may be 'at risk' of experiencing) a 'first episode of psychosis'. These services often have age-range criteria. Traditionally services have been youth-focused (for example, aged 14-35), however this has widened to 14-65 in England (NICE, 2014). EIS should aim to offer a "range of psychological, pharmacological, social, and occupational interventions; place emphasis on engagement rather than risk management; provide treatment and care in the least restrictive and stigmatising environment possible and in an atmosphere of hope and optimism" (NICE, 2014, p. 28). EIS also work with families and support networks. Continuity of care is an important component of EIS and people who access these services

are allocated to a key worker, also known as a care co-ordinator, and are commonly

supported by an EIS for three years (NHS England, 2016).

Effectiveness of EIS

EIS are developing an evidence-base supporting their effectiveness in improving

clinical and social outcomes (Bird et al., 2010; Garety et al., 2006). Specifically, accessing

EIS appears to reduce an individual's 'symptoms' (Grawe, Falloon, Widen, & Skogvoll,

2006), their number of hospital admissions (Bertelsen et al., 2008), and can lead to

improved social outcomes, such as housing and employment (Bertelsen et al., 2008; Bond,

Drake, & Luciano, 2015). Individuals who access EIS have also self-reported significant

improvements on measures of quality of life and higher levels of satisfaction with their

treatment compared to those accessing a generic mental health service (Garety et al.,

2006). For simplification and to avoid the use of labels, the words 'individual' and

'individuals' will hereafter be used exclusively to describe people who access EIS, often

referred to as 'service users' in the literature. Exceptions will be specified and direct

quotes from other studies may use this term.

Despite this growing body of research, the EI approach is not without its criticisms.

There is limited evidence that its positive outcomes are maintained in the long-term (Bird

et al., 2010). One large randomised controlled trial (RCT) carried out in Denmark found

that the benefits of accessing an EIS can dissipate after five years (Hildreth & Fellow,

2008). Hildreth and Fellow (2008) suggest that this is the result of a lack of transitional

support as individuals are discharged from EIS. Despite their focus on engagement, EIS

experience similar rates of disengagement (about a third) to other mental health services

(Kreyenbuhl, Nossel, & Dixon, 2009; Stowkowy, Addington, Liu, Hollowell, &

Addington, 2012). Another aspect of the EI approach which has been questioned is the

administration of antipsychotic medication as recommended practice (Francey et al., 2010;

NICE, 2011). While some individuals have experienced the prescription of psychiatric

medication as positive, others have felt coerced into taking medication (Das, Malik, &

Haddad, 2014).

Individuals' Experiences of Mental Health Services

Increasingly, national guidelines and clinical practice within mental health have

focused on large-scale quantitative research in determining which interventions are deemed

to be 'evidence-based'. At the same time, there has been a push to include the views and

experiences of individuals and families when evaluating evidence-based interventions

(Berry & Hayward, 2011; Timulak, 2009).   Conducting qualitative research focusing on

people's experiences of accessing mental health services can provide unique insight into

how services function in clinical practice. While quantitative research is well placed to

answer questions about *whether* a service is helpful or effective, qualitative research can

answer key questions about *how* and *why* they might be helpful.

Despite the growing emphasis on qualitative research in mental health, very few

systematic reviews exist looking at people's experiences of accessing specific mental

health services. I could only find two such reviews, both of which looked at the

experiences of people who had received a diagnosis of 'borderline personality disorder'

(BPD; Katsakou & Pistrang, 2017; Stapleton & Wright, 2017).   These reviews provided

insight into the elements of services which: promoted positive change and recovery; were

valued by individuals; and were viewed as unhelpful. Newman et al. (2015) conducted a

broader review across a range of inpatient and community mental health services,

emphasising the importance of continuity of care and building relationships between individuals accessing services and professionals.

Outside of these systematic reviews, there are a number of service- and diagnosis-specific qualitative studies exploring people's experiences of mental health services. The importance of relationships with professionals has been expressed by individuals within inpatient settings (Gilburt, Rose, & Slade, 2008) and by individuals who have received an 'eating disorder' diagnosis (Escobar-Koch et al., 2010; Wright & Hacking, 2012). In contrast however, one study with individuals with a diagnosis of 'bipolar disorder' revealed predominantly negative experiences, such as feeling stigmatised by professionals, a lack of collaborative working, and discontinuity of care (Highet, McNair, Thompson, Hickie, & Davenport, 2004). This qualitative research, which focused on the perspectives of people who accesses mental health services, has been able to highlight important relational and systemic aspects of different mental health services. In doing so, these studies have contributed to a deeper understanding of these services at a holistic level.

As mentioned previously, there is a growing body of quantitative research looking at the effectiveness of EIS at a whole-service level (Bird et al., 2010; Garety et al., 2006). For example, participants in Garety et al. (2006) all accessed an EIS, however each person was offered a unique, individualised treatment programme which comprised of a range of interventions, such as psychiatric medication, psychological therapy, or vocational and social support.   Gathering this type of whole-service evidence about the effectiveness of EIS as an approach is important.   However, as exemplified above, qualitative research also has a key role in better understanding some of the more complex relational and systemic processes of services at a holistic level. Specifically, qualitative research might be best

placed to gain insight into the application of the underlying principles of EIS, such as

engagement and engendering hope (NICE, 2014), which represent complex relational

phenomena which are difficult to explore through quantitative methods.   Listening to the

voices of individuals provides an indication of how these principles translate into clinical

practice and individual care. Furthermore, there has been a recent call to apply the EI

approach to other psychiatric diagnoses and areas within mental health (McGorry, 2015).

Thus, it seems an especially important time to 'take stock' of how individuals experience

EIS. Conducting a review of the current state of qualitative research looking at

individuals' experiences of accessing EIS is thus an important 'next step' in contributing to

the evidence-base and wider understanding of EIS. Korhonen and colleagues (2013) argue

that qualitative reviews, or meta-syntheses, are an important part of evidence-based

practice.

A preliminary literature search found that some qualitative research has already

been conducted focusing on personal experiences of accessing EIS generally (Harris,

Collinson, & das Nair, 2012; Lester et al., 2011), while other studies have focused on

specific aspects, such as engagement (van Schalkwyk, Davidson, & Srihari, 2015). These

articles will be described in more detail within this review.

It is important to note that at the time of conducting this systematic review, no existing

meta-synthesis had been published looking at individuals' experiences of accessing EIS.

However, following the completion of both the literature search and analysis, one such

review was published by Hansen and colleagues (2018). The findings from the Hansen et

al. (2018) meta-synthesis will be compared and contrasted with the findings of the present

review in the discussion section of this paper. **This Meta-Ethnography**

This paper utilised a process of meta-synthesis in order to systematically review the

qualitative research into individuals' experiences of EIS. The meta-synthesis attempted to

answer the question: What are individuals' experiences of accessing EIS? Meta-synthesis

is a method of combining data and findings across similar qualitative studies with the aim

of developing a greater understanding of a particular research question (Walsh & Downe,

2005). Meta-syntheses are important because they may expand the generalisability of

qualitative studies and improve the dissemination and overall impact of findings (Jones,

2004). There are a number of different methods which can be used when conducting a

meta-synthesis. This review adopted a meta-ethnography methodology, an approach which

places a particular emphasis on making broader interpretations and developing theoretical

insights which go beyond the findings of the individual studies included in a review

(Noblit & Hare, 1988). Mays, Pope, and Popay (2005) view meta-ethnographies as

playing a role in influencing wider healthcare policy. Conducting a meta-ethnography in

relation to the EI approach could also be helpful to individuals who are about to access an

EIS, providing lived accounts from individuals who have experience of these services

(Berry & Hayward, 2011).

This meta-ethnography included research conducted internationally. A previous

meta-synthesis of people's experiences of inpatient mental health services showed that

despite differences in how services are organised between countries, there were many

overlapping and consistent themes (Stapleton & Wright, 2017). Although the review was

written from a largely England-based perspective, looking at experiences within

international EIS could provide insight into what makes for a helpful, effective, and valued

EIS. In fact, Britten et al. (2002) argue that including studies carried out across a range of

settings is important in meta-syntheses in order to improve the applicability of findings.

Method

The following electronic databases were searched to find the identified articles:

Academic Search Ultimate, AMED, CINAHL, EMBASE, PsycINFO, PUBMED,

SCOPUS, Web of Science. All searches were completed up until 8th July 2017. The

search strategy can be found in Table 1. Keywords, thesaurus, and Medical Subject

Heading (MeSH) terms were used for databases where possible (see Table 1). The terms

used in the 'EI' component of the database searches were informed by names for EIS

adopted internationally (IEPA Early Intervention in Mental Health, 2017; McDaid, Park,

Iemmi, Adelaja, & Knapp, 2016). However, I am aware that there are many different

names for EIS and it is likely a number of these were not included in the search. In an

attempt to account for this, all terms were searched for in 'full-text' where possible, with

the assumption that an article looking at an EIS would mention one of the key 'EI' search

terms. The terms included in the search to retrieve qualitative studies were informed by

previous literature investigating optimum search strategies for retrieving qualitative studies

(Evans, 2002; Shaw et al., 2004). Shaw et al. (2004) discuss a trade off between sensitivity

and comprehensiveness when searching for qualitative literature. In this review, a 'broad'

and comprehensive strategy was adopted to ensure that any relevant articles were not

missed. The search process can be found in Figure 1. Eleven articles were identified

through the search and were included in this review. Study characteristics can be found in

Table 2.

Eligibility Criteria

The inclusion criteria in this study were: a) the study adopted a qualitative methodology, b) the study was published in a peer-reviewed journal, c) the study was published in English, d) the study was interested in individuals' experiences of accessing an EIS, including their relational experiences of EIS (such as engagement). The inclusion criterion (d) was specified because this meta-synthesis was interested in exploring some of the complex, relational processes within EIS, such as engagement and engendering hope.

Articles were excluded if they met one of the following: a) the study was published as a conference abstract and was not available in full-text; b) the study was interested in a specific intervention or component of an EIS rather than people's overall experiences of accessing EIS. An intervention was defined as a distinct element of support offered to or undertaken by a 'service user' as part of their care within an EIS. When accessing an EIS, individuals may be offered or take part in different aspects of the service, such as psychological therapy, social groups, antipsychotic medication, or employment support. Each individual who accesses EIS will engage with different interventions and elements of the service depending on their personal need. Certainly, an EIS could be viewed as the 'sum of its parts' and there is definite value in looking at individuals' experiences of these specific elements within an EIS. However, this meta-synthesis aimed to only include studies which explored individuals' experiences of EIS as a whole, aiming to look at broader themes at a service-level. Of course, this could include individuals' experiences of specific interventions, but also might include experiences of engagement and relationships with EIS staff which go beyond specific interventions. As such, this meta-synthesis aimed to allow exploration of the processes and aspects of EIS that individuals valued and found

helpful when the service is viewed holistically. It also aimed to lead to a better

understanding of individuals' journeys within EIS; c) the study was interested in people's

experiences of a mental health service which was not an EIS; d) the study did not focus on

people's experiences of accessing EIS.

Analysis

In order to synthesise the included qualitative studies, a meta-ethnographic

approach was adopted following the seven step process outlined by Noblit and Hare

(1988): "(1) getting started; (2) deciding what is relevant to the initial interest; (3) reading

the studies; (4) determining how the studies are related; (5) translating the studies into one

another; (6) synthesizing translations; (7) expressing the synthesis" (Noblit & Hare, 1988,

pp. 26-29).

After identifying the 11 relevant studies, I read and re-read each article to

familiarise myself with the studies. During this, I extracted key concepts and themes from

each study and entered them into a table. In doing this, I drew on the concept of first-,

second-, and third-order constructs described by Britten et al. (2002).   First-order

constructs represent the experiences expressed by participants through direct quotes.

Second-order constructs are the interpretations of these experiences made by the authors of

the included study. Third-order constructs are my own interpretations of the first- and

second-order constructs (Malpass et al., 2009).   The first- and second-order constructs

extracted from the studies can be found in Table 3.

Previous authors have acknowledged that the methodological framework provided

by Noblit and Hare can be vague about exactly how to 'translate studies into one another'

(Atkins et al., 2008). I navigated this issue by drawing on a previous paper which looked

at reciprocal translation and reviewed and critiqued different approaches across meta-ethnographies (Melendez-Torres, Grant, & Bonell, 2015). This meta-ethnography combined two of the approaches mentioned by Melendez-Torres and colleagues. First, a 'thematic and conceptual grid' was created in a Microsoft Excel spreadsheet. This grid contained first- and second-order constructs from the studies and was used to group these constructs into larger themes. This was an iterative process of reorganisation, ensuring that the themes were congruent with the encompassed concepts from the studies. I also utilised Noblit and Hare's (1988) ideas of reciprocal and refutational translations, which involve looking for overarching and contradictory themes respectively. The other method of reciprocal translation adopted was a visual representation or map. This map was developed during the third-order analysis to help me visualise how the themes, concepts, and studies might be related. This method of analysis was influenced by previous meta-ethnographies which adopted a similar grid and map approach (Lamb, Bower, Rogers, Dowrick, & Gask, 2012; Malpass et al., 2009). This third-order synthesis mapped onto what Noblit and Hare (1988) term a 'line-of-argument': a synthesis which attempts to put forward a theory about the social processes at play across the studies.

Critical Appraisal

In this meta-ethnography, I adopted the critical appraisal criteria outlined by Kitto, Chesters, and Grbich (2008). These criteria are broken down into six areas which are defined in Figure 2. The six sub-criteria assess methodological issues, as well as the depth and clarity of the presented concepts and themes. The method of critical appraisal chosen here covers, and indeed goes beyond, the questions included in the widely used Critical Appraisal Skills Program (CASP) tool (CASP, 2011).

There is little consensus over how critical appraisals should be conducted in meta-syntheses (Toye et al., 2013). Carroll and Booth (2015) have put forward sensitivity analysis as a 'risk-averse' means of assessing quality in light of the lack of evidence for any one given method. Sensitivity analysis is a process which looks at the quality and relative contribution of each study to the overall findings of a meta-synthesis. The aim in doing this is to assess whether a review's findings have been influenced by one or more poor quality studies. Sensitivity analysis was performed post-synthesis utilising the Kitto et al. (2008) tool (Figure 2). Appendix 1-A provides the outcome of this tool. Articles were not excluded from the review on the basis of a subjective judgment of their 'quality'. The decision to include all relevant articles was also driven by a desire not to exclude the voices and experiences of study participants based on methodological decisions made by the researchers who recruited them.

Findings

First- and Second-Order Synthesis

A thematic and conceptual grid was developed (Table 3) to group the translated first- and second-order constructs across the studies into themes (Melendez-Torres et al., 2015). Pertinent direct quotes from participants have been used to illustrate the themes and sub-themes. Appendix 1-B provides an example of how each included study was deconstructed as part of the analysis. Appendix 1-C provides an example of how the themes and sub-themes were developed based on the included studies.

Theme 1: Understanding Through Relationships

Sub-theme 1.1: 'There to listen': Importance of relationships. All studies found that individuals' relationships with EI staff, and often with one specific care co-ordinator,

were a highly important part of their experience of EIS. An overarching concept across

many of the studies related to EI staff 'being there' - that staff were available, accessible,

and dependable: "even in the night when we call, they were always there" (individual in

Islam, Rabiee, & Singh, 2015, p. 746). Indeed, Lester et al. (2012) interpreted this as

representing "certainty at a time of great uncertainty" (p. 185).

The second aspect of individuals' relationships with staff was that they were not

only there to listen, but that individuals felt heard. The stance which staff members

adopted also appeared important to individuals. The ability of EI staff to 'be human' was

valued: "She's [EI care co-ordinator] very human…she didn't put up a wall between

what's professional and private" (individual in Stewart, 2012, p. 341). Lucksted et al.

(2015) developed a concept of 'warm respect' to represent this, characterised by a position

of "friendliness, interest, patience, and sincerity" (p. 701). An individual in this study

described EI staff as being "very kind people and very inviting, very caring, very genuine"

(p.701). These factors were also discussed alongside feelings of attachment and trust

towards staff. A theme for individuals in one study was that they felt loved by their key

worker (O'Toole et al., 2004).

In two studies (Stewart, 2012; Windell & Norman, 2012), individuals also

experienced 'being heard' in the context of relationships with 'peers', that is, other

individuals accessing EIS. Peers' ability to listen non-judgementally and provide unique

empathy, compassion, and understanding was highly valued by individuals. Furthermore,

individuals experienced peers as being able to listen and 'truly' understand them in a way

that EI staff without lived experience of psychosis could not (Windell & Norman, 2012).

Relational themes of attachment, trust, and feeling heard were often followed by

individuals feeling able to 'open up' to EI staff about their emotional distress and experiences of 'psychosis'. "I knew that I could finally show everybody, I could tell what was really going on and they understood" (individual in Allard, Lancaster, Clayton, Amos, & Birchwood, 2016, p. 4). However, two studies outlined negative experiences relating to individuals developing a close and trusting relationship with their co-ordinator, only to have this relationship broken due to high levels of staff turnover (Islam et al., 2015; Lester et al., 2011). More importantly to individuals however, was that they were having to open up repeatedly and retell their life stories, a process which was experienced as disruptive and "traumatic" by several individuals (Islam et al., 2015, p. 746). Allard et al. (2016) was the only other study in which some individuals did not develop good relationships with staff and experienced a lack of support from EIS. These authors believed that the current EI model was not the appropriate means of support for these individuals and argued that EI staff should be able to be more flexible in their approach. Overall, individuals appeared to view their relationships as positive, meaningful, and central to their experience of accessing EIS. Despite EI being a 'complex' approach (Larsen, 2007), the importance of relationships with specific key workers was viewed by O'Toole et al. (2004) as indicative of EI being a "primarily relationship-based and highly individualised" (p. 323) intervention.

Sub-theme 1.2: Explanations and understanding. Almost all studies included themes and concepts related to staff members providing individuals with an explanation for their experiences of psychosis. "Once I was with the EIS team they explained what was going on and what I was going through" (individual in Lester et al., 2012, p. 185). In

Windell and Norman (2012), this understanding was also experienced through relationships with other individuals accessing EIS.

Across the studies, a variety of frameworks for understanding 'psychosis' were provided by staff to individuals, incorporating biomedical, cognitive behavioural, and psychosocial explanations of 'psychosis', with these being experienced as helpful by individuals. Forming an understanding of their experiences allowed some individuals to move to a place of acceptance of their 'symptoms'. However, this acceptance was sometimes coupled with a sense of being resigned to "a life with psychosis" (Harris et al., 2012, p. 463). In Larsen's (2007) analysis, an important aspect of these explanatory models was that staff members interpreted and applied these understandings differently for each individual in a personalised manner. As described by Windell and Norman (2012, p. 496), this information was most helpful when it was "personalised" to each individual's need. Biomedical explanations were sometimes combined with an individual's cultural and spiritual beliefs to provide an "individually satisfying explanatory model" (p. 342).

A markedly different finding was provided by Islam et al. (2015), which, along with Larsen (2007), was the only other study to mention cultural or spiritual models of 'psychosis'. Individuals in Islam et al. reported actively withholding their spiritual beliefs for fear that they would be interpreted as 'delusional symptoms' of 'psychosis'. Not feeling able to talk openly about how their cultural beliefs fit with other models of understanding left one individual confused about why they experienced 'psychosis': "I still don't quite understand why I got ill" (Islam et al., 2015, p. 745).

The process by which this explanation was developed was found to be important to individuals. In van Schalkwyk et al. (2015), it appeared that an explanation that an

individual had an 'illness' was *given* to individuals rather than developed collaboratively. In this case, EI staff were offering individuals treatment for their 'illness', before individuals had considered themselves as having an 'illness'. The authors note that this mismatch impacted negatively on an individual's engagement with EI (van Shalkwyk et al., 2015). However, when an understanding and explanatory model was developed collaboratively and was individualised, this helped individuals to develop an understanding of their experiences, as well as an understanding of themselves (Lester et al., 2011).

Theme 2: Recovery and Hope

  Sub-theme 2.1: Practical support. In the majority of studies (excluding Allard et al., 2016; Islam et al., 2015), support with practical issues, such as employment, education, social life, housing, and finances, represented a highly significant theme within an individual's experiences of EIS. Van Schalkwyk and colleagues (2015) interpreted these aspects of EIS as more important and valued by individuals than improving their psychological difficulties or 'symptoms'. However, O'Toole et al. (2004) reported that symptom reduction, alongside practical support, represented an important part of individuals' recovery process. According to Lucksted et al. (2015), receiving help with the life goals of individuals, whether educational, vocational, etc., was crucial in engaging individuals in EIS. An individual in Windell and Norman (2012) noted the importance of EI staff doing "whatever is allowed" (p. 496) to assist with these goals, in this instance, driving the individual to a job interview. However, in their analysis they also recognised that some individuals' goals were incompatible with engagement with EI, citing an example of an individual whose goal of full-time employment conflicted with attending sessions. Larsen (2007) viewed this practical support role of EI staff as helping

individuals to plan their future lives, something which Lester et al. (2012) believed gave

individuals a sense of hope for the future.

Sub-theme 2.2: Hope and the future. A number of studies explored individuals'

sense of hope about the future, which ranged from optimistic to hopeless. Lester et al.

(2012) discussed EIS engendering hope, providing belief in a "life after psychosis" (p.

186). Being able to once again participate in the life activities which they used to take part

in gave individuals a belief in themselves going forwards (O'Toole et al., 2004). As

mentioned above, this hope was sometimes facilitated by practical support. In another

study, individuals used their own explanatory model of 'psychosis' to foster hope (Larsen,

2007). Specifically, Larsen (2007) noticed that individuals drew on different, sometimes

competing, models of 'psychosis', making use of both episodic and chronic narratives

around 'psychosis' when it helped them to feel hopeful about their future. Windell and

Norman (2012) viewed the hopeful atmosphere of EIS as equally as important as the

interventions offered to individuals.

Attending 'peer' groups with other individuals accessing EIS was also important to

fostering a sense of hope, and importantly 'solidified' engagement with EIS (Stewart,

2012). Speaking with and learning from peers appeared to increase individuals'

expectations of hope (Windell and Norman, 2012) and provided individuals with the

"chance to experience a collective determination towards recovery" (Stewart, 2012, p.

343). Contrasting with these positive expressions of hope, individuals in Islam et al. (2015)

conceptualised hope through expectations of a 'cure'; when EIS could not provide this,

they stopped engaging with the service. Allard et al. (2016) noted that although

individuals expressed a sense of relief that they were 'recovering', most were tentative

when making projections about their futures.

Theme 3: Sense of Self

      Sub-theme 3.1: Identity. The impact that experiencing 'psychosis', and

subsequently accessing EIS, had on individuals' identity was a theme in several studies.

Larsen (2007) provided a vivid account of this: "psychosis had destabilized their sense of

self and…introduced a radical social renegotiation of identity " (p. 342). In both O'Toole

et al. (2004) and Stewart (2012), identity was a rich theme within their findings; accessing

EI support helped individuals to separate their 'illness' from their own identity. An

example of the influence of EIS on identity and a sense of self came from an individual in

Stewart (2012): "I started to feel like I was worthwhile" (p. 341). O'Toole et al. (2004)

outlined the important role which EI staff played in this: "Service users' involvement with

the team provided an important source of self and social validation as self-respecting

human beings" (p. 323). The peer support groups facilitated by EIS also played a role in

allowing individuals to share their experiences of altered identity with other individuals

(Lester et al., 2012; Stewart, 2012; Windell and Norman, 2012). Interestingly, these

changes to identity were not only related to their 'psychosis', but also to aspects of their EI

treatment. Specifically, individuals commented on the detrimental effect of medication-

related weight gain. In Harris et al. (2012), accessing EIS allowed one individual to

develop a new, stronger sense of identity compared to who they were before. Similarly,

Windell and Norman (2012) described EIS as helping individuals to "repair [a] sense of

self" (p. 496). In the same study however, other individuals did not experience the same

positive growth, feeling that their identity remained affected by their 'psychosis', leaving

them feeling "incompatible with the world" (p. 465).

      Sub-theme 3.2: Independence/dependence. This sub-theme reflects the various

concepts and themes related to the two sided coin of independence and dependence. In

Larsen (2007), the process of being discharged was a key step in one individual's journey

in that it helped them to live independently of EIS. Some participants in Lester et al.

(2012) echoed this, feeling that EIS had supported them to be ready for their discharge and

to 'move on'. O'Toole et al. (2004) found that individuals experienced growing

confidence as a result of gaining independence. This was suggested to have been

facilitated by engagement with employment, education, and social activities. In Harris et

al. (2012) independence was facilitated by an increased sense of agency and responsibility

for individuals' own lives. "They've (EIS) offered me support in every area…but…there

is no one who can actually provide the solution other than yourself" (p.464). Providing a

juxtaposition to these themes of independence and agency, Lester et al.'s (2012) findings

suggested that some individuals experience the high levels of support offered by EIS as

leading to feelings of dependence on the service. "I think if I'm honest I was sort of

starting to perhaps become a little bit dependent on them" (individual in Lester et al., 2012,

p.186). It is interesting to note that this was the only study focusing on individuals who

were 'past service users'. It is possible that having some 'distance' from EIS might have

allowed individuals to reflect on their relationship to the service and experiences of

(in)dependence. Other individuals who were early in their EIS journey expressed

uncertainty about their ability to live independently again (Allard et al., 2016).

      Sub-theme 3.3: Stigma and normalisation. Five studies discussed the

stigmatising impact of accessing an EIS, which was often interwoven with the stigma surrounding 'psychosis' itself. In Lester et al. (2012), although individuals experienced positive relationships with EI staff, the fact that most of their social interactions were with mental health professionals, rather than friends, had an effect on individuals. High levels of EI staff engagement provided individuals with a reminder of their 'service user' status: "as I've got better it's not nice having somebody come in all the time, because it constantly reminds me that you're suffering from an illness" (individual in Lester et al., 2011, p. 884). There was also a degree of stigma and shame associated with accessing an EIS: "I feel as though it's not [mainstream], I feel as though it's some kind of little special group that needs to be taken aside cus [sic] they need that extra remedial lesson type thing" (individual in Harris et al., 2012, p. 462). Individuals in Harris et al. (2012) also described a hierarchy of psychiatric diagnoses; that accessing a specialist service meant that individuals had a 'worse' mental health problem than people who access mainstream services. Contrasting themes of stigma were presented by Harris et al. (2012) and Stewart (2012), which suggested that individuals' experiences of stigma diminished as they spent more time within EIS and began to think differently about 'psychosis' and mental health services. O'Toole et al. (2004) also mentioned EIS's positive impact on stigma through adopting a collaborative approach and involving individuals in treatment decisions.

Three studies discussed the role of EIS in normalising individuals' experiences of 'psychosis'. In Allard et al. (2016) EI staff played a key role in explaining to individuals that others had gone through the same thing. For individuals in three studies (Harris et al., 2012; Stewart, 2012; Windell and Norman, 2012), this normalising role was played by other individuals, who shared experiences with each other in peer support groups

facilitated by the EIS. Meanwhile, a different form of normalisation was described by van

Schalkwyk et al. (2015), which viewed the positive relationships between individuals and

staff outlined in Sub-theme 3.1 as normalising individuals' 'need for care'.

Theme 4: Medication

All but two studies (Allard et al., 2016; Stewart, 2012) contained findings related to

anti-psychotic medication, a common component of an EIS support plan. However, the

way in which individuals discussed medication varied considerably between studies. In

two studies (Lester et al., 2012; Lucksted et al., 2015), individuals felt supported by EIS in

relation to medication. In both Lucksted et al. (2015) and Windell and Norman (2012),

many individuals were actively involved in decision making around medication; the

authors viewed this as promoting engagement. Conversely, van Shalkwyk et al. (2015)

and Harris et al. (2012) both reported that individuals experienced EIS as being coercive

and overmedicating; this had an adverse effect on individuals' engagement. Windell and

Norman also described some individuals adopting a more 'passive' role in their

medication, preferring to "leave medication decisions in the doctor's hands" (p. 496). One

individual in Harris et al. (2012) described her lack of choice over taking medication: "it

feels as though . . . everything is being taken out of your hands and you just . . . feel

worthless really (p. 464). Weight gain was mentioned as an unwanted side effect of

medication in two studies and this had a negative impact on identity in both findings

(Lester et al., 2012; Lester et al., 2011). In Larsen (2007) and Islam et al. (2015),

individuals experienced medication as helpful but 'not enough'. For some individuals their

expectations of medication appeared related to wanting a 'cure' (Islam et al., 2015). While

others viewed medication as helpful but only in combination with receiving support within

EIS (Larsen, 2007). Similarly, van Schalkwyk et al. (2015) found that medication was perceived as helpful with symptom reductions, but not as central to their recovery process as social factors, such as employment etc. Some studies observed that individuals were offered alternatives to medication and that this was valued. However, individuals in another study felt that EIS gave them few treatment options other than medication (Harris et al., 2012).

Third-Order Synthesis

My interpretation of how the above first- and second-order concepts relate to each other is shown in the form of a conceptual map in Figure 3, which is accompanied by Appendix 1-D. This map can be viewed as a timeline, following an individual's journey and experiences into, through, and out of an EIS. This journey is expressed through four third-order concepts. It is important to note that the map represents a simplification of one possible journey through and out of EIS. In reality, individual journeys are non-linear, multi-layered, and complex (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011).

Stage 0: Point of accessing EIS. Although not directly related to individuals' experiences of EIS, this concept has been included to provide context to individuals' journeys and the role EIS play in these. Across all the studies, two overarching factors were valued most highly by individuals: relationships (Sub-them 1.1) and practical support (Sub-theme 2.1). This might provide an indication of some of the elements that were missing or 'going wrong' in individuals' lives prior to accessing EIS. Indeed, loss of social relationships (Macdonald, Sauer, Howie, & Albiston, 2005), feelings of social exclusion (Schulze & Angermeyer, 2003), high unemployment rates (Ramsay, Stewart, & Compton, 2012; Reininghaus et al., 2008), and significant levels of housing need and homelessness

(Harvey, Killackey, Groves, & Herrman, 2012) have all been reported in research with

people experiencing a 'first episode of psychosis'. Furthermore, the importance that

individuals placed on developing an understanding of 'psychosis' through their

relationship with staff and feeling able to 'open up' (Sub-theme 1.2) is suggestive of

individuals entering an EIS with feelings of confusion, uncertainty, and an "existential

crisis of becoming mentally ill" (Larsen, 2007, p. 342). The importance of normalisation

and overcoming stigma (Sub-theme 3.3) also suggests that individuals enter EIS with a

negative view of themselves due to experiencing 'psychosis'.

     Stage 1: The importance of relationships. For the majority of individuals, the

first, and perhaps most important, aspect of their EIS experience was developing a

relationship with a specific EI staff member (Theme 1). The process of forming this

relationship was characterised by the staff member's availability and ability to listen.

Feeling heard may have been facilitated by the stance adopted by EI staff (Sub-theme 1.1).

A non-judgemental stance was particularly valued, perhaps because individuals might have

experienced feelings of judgement from friends and family prior to this, as expressed in

Islam et al. (2015) and Harris et al. (2012). This also fits with previous qualitative research

indicating that individuals can face significant levels of judgment, stigma, and

discrimination from their family and friends, as well as from mental health professionals

and members of the general public (Dinos, Stevens, Serfaty, Weich, & King, 2004;

Schulze & Angermeyer, 2003). As trust developed between individuals and EI staff,

individuals talked more openly about their experiences, which then helped them to

understand their experiences (Sub-theme 1.2). EI staff also played a role in normalising

individuals' experiences by sharing stories of other people they had worked with.   Other

valued relationships experienced by individuals were with other 'peers' within peer support

groups, such as in Stewart (2012) and Windell and Norman (2012). These groups helped

individuals to feel normalised and provided an opportunity to share difficulties and

challenges. Normalising individuals' experiences was linked with reducing feelings of

stigma (Sub-theme 3.3).

     Stage 2: A collaborative and person-centred intervention. Alongside key

relationships, the other aspects of EIS which were highly valued and viewed as most

helpful were *practical support* (Sub-theme 2.1) and developing an *explanation and*

understanding (Sub-theme 1.2) for individuals' experiences of 'psychosis'. The use of

psychiatric *medication* (Theme 4) was mentioned across all studies and while individuals

had varying views on its role in their care, it was certainly a significant part of their

experience of EIS.

     Across these three domains, an overarching third-order concept of *a collaborative*

and person-centred intervention was developed. This concept appeared to be incredibly

important in ensuring that the EI approach was experienced as helpful by individuals. The

ability of EI staff to offer collaborative and person-centred interventions depended on

developing strong relationships between EI staff and individuals, through which staff could

'get to know' individuals (Theme 1). This then allowed individuals to trust in the staff and

subsequently the service. Practical support was most beneficial when it reflected the

personal goals and interests of individuals, based on discussions between individuals and

their key workers (Sub-theme 2.1). Understandings and explanations were most helpful

when EI staff drew on both the personal experiences and beliefs of individuals, and staff's

own theoretical understandings and models of 'psychosis' (Sub-theme 1.2). This allowed

individuals and EI staff to develop a shared understanding of an individual's experiences. These processes were less helpful when individuals did not trust their key worker enough to talk about their own beliefs, and when an explanatory model of 'psychosis' did not fit with individuals' understanding at that time and was given rather than developed collaboratively. Medication was experienced as helpful when: individuals had input over their medication; it fit with their view of themselves as 'in need of psychiatric help'; and it helped them to engage in meaningful social and vocational activities (Theme 4).

Stage 3: Life beyond EIS. Another important part of the EIS journey was considering *life beyond EIS*. Significant themes across studies related to the role of EIS in: fostering a sense of *hope (Sub-theme 2.2)*; influencing individuals' sense of self and *identity* (Sub-theme 3.1); and developing a feeling of *independence* (Sub-theme 3.2). All of these elements were influenced, both positively and negatively, by the processes in Stage 2. For example, the explanation developed for an individual's experiences of 'psychosis' could both foster and reduce feelings of hope (Sub-theme 2.2). Similarly, medication could support individuals to engage with meaningful activities, but could also negatively impact on an individual's identity (Theme 4). There also appeared to be a fine balance between EIS offering enough support to allow individuals to move towards independent living and offering a level of support which left individuals with a feeling of *dependence* on the service (Sub-theme 3.2).

Discussion

The third-order map as a whole echoes the findings of previous qualitative research and meta-syntheses looking at individuals' experiences of mental health services. The importance of staff relationships is a major theme across numerous studies and reviews,

regardless of the type of mental health service (Gilburt et al., 2008; Hansen et al., 2018; Katsakou & Pistrang, 2017; Newman et al., 2015; Stapleton & Wright, 2017). Providing particular support for the findings of this meta-ethnography, a broad review of mental health services concluded that relationships between individuals accessing services and professionals serve as a foundation for the support and interventions offered by mental health services, particularly when individuals accessing services are active collaborators in their care (Newman et al., 2015). The benefits of adopting a collaborative approach emerged clearly in the third-order synthesis. Previous research has found that being more actively involved in one's care can lead to greater self-confidence (Dahlqvist-Jönsson, Schön, Rosenberg, Sandlund, & Svedberg, 2015; Katsakou & Pistrang, 2017). However, when people do not feel that they are collaborative partners in their care, they can feel incompetent, as well as coerced and controlled by mental health services (Dahlqvist-Jönsson et al., 2015; Katsakou & Pistrang, 2017).

Relationships with other individuals accessing EIS also appeared to be significant for individuals in the included studies. Previous studies have found that these 'peer relationships' can serve as a unique source of emotional support which could not be offered by people who had not experienced mental health difficulties (Hansen et al., 2018; Stapleton & Wright, 2017). In this review, individuals' relationships with both EI staff and other individuals accessing EIS provided normalisation around 'psychosis'. The synthesis linked this normalisation with feelings of stigma. This was influenced by previous research suggesting that stigma and normalisation are interrelated concepts (Joachim & Acorn, 2000). Joachim and Acorn (2000) view normalisation as a process which occurs in response to experiences of societal stigma surrounding a particular 'illness'. In the present

meta-ethnography, this process was facilitated by EI staff and through interactions with peers.

One interesting tension which came out of the analysis related to the role of EIS in making some individuals feel more independent. A focus on supporting individuals to engage in activities outside of EIS, such as employment, education, social life, appeared important in facilitating independence. Feelings of agency and self-responsibility were also associated with independence. On the other hand, some individuals felt as if they were becoming dependent on the service. Focusing on EIS-centred activities, such as medication appointments or psychological therapy, or adopting a paternalistic approach towards individuals' wellbeing which might limit feelings of agency and self-responsibility, could be hypothesised as being more likely to lead to dependence. There appears to be a balance in the amount of support and engagement that EIS provide to individuals, a dilemma mentioned previously (O'Brien, Fahmy, & Singh, 2009). Similar themes of dependence on services have been provided by Stapleton and Wright (2017) in their review of individuals with a diagnosis of 'BPD' accessing inpatient services.

Two Delphi studies, one international (Addington, McKenzie, Norman, Wang, & Bond, 2012) and one UK-based (Marshall, Lewis, Lockwood, & Fiander, 2004), have synthesised the opinions of a panel of 'EI experts-by-profession' from research and clinical backgrounds with the aim of determining which elements of EIS were 'essential'. These essential components are too varied to be summarised here, but included: comprehensive assessment and care plan, antipsychotic medication, psychological therapy, psychoeducation, and education and vocational plans. Although there are some similarities between this list and the factors which appeared to be most important to individuals in the

current review, there are two notable disparities. First, experts did not view staff and peer

relationships as an essential component of EIS. Second, experts in Addington et al. (2012)

placed far more importance on pharmacological interventions compared with individuals

who took part in the included studies. This provides an indication of the difference

between the goals of EIS and those of individuals, as suggested by Harris et al. (2012).

That is, EIS appear to have a greater focus on 'symptom reduction' compared to

individuals, who are more interested in making social and practical changes to their lives.

Being supported to make practical changes appears to have a close relationship with

fostering a sense of hope, both in this meta-ethnography and a previous meta-synthesis

interested in the experiences of individuals with a diagnosis of 'BPD' (Katsakou &

Pistrang, 2017). The emphasis on making practical changes reflects one of the tenets of the

Recovery movement, which views the process of recovery as "recovering a life" (Slade et

al., 2014, p. 14) rather than recovering from a 'mental illness'. Regardless of whether EIS

adopt a 'Recovery-based approach', the current findings suggest that services should

ensure that their approach is in line with the goals and needs of individuals.

As mentioned earlier, it was an aim of this meta-ethnography to test some of the

underlying principles of the EI approach (see Introduction). The findings suggest that

these ideas are generally put into practice. Engagement could be conceptualised as

existing through the strong relationships between individuals and EI staff, and themes

around risk management were not evident. Although hope and optimism were not

universally present, it is evident that when EIS embody collaborative and person-centred

practice, they certainly have the potential to engender these feelings.

Comparison with Hansen et al. (2018) Meta-synthesis

As noted earlier, Hansen et al. (2018) recently published a meta-synthesis with a slightly broader focus than the present meta-synthesis: exploring people's experiences of accessing EIS in relation to their experiences of personal recovery. This meta-synthesis was published after I had completed the search and analysis processes. It is thus important to look at the major similarities and differences between the present review and that conducted by Hansen et al. (2018). Hansen et al. (2018) review included 17 studies, 10 of which were not included in the present review. However, the present review included four studies (Allard et al., 2016; Islam et al., 2015; Larsen, 2007; Lucksted et al., 2015) which were not included in Hansen et al. (2018). This discrepancy highlights previously noted difficulties searching for qualitative studies (Shaw et al., 2004). The difference in the included studies could be explained by differences in search strategy and inclusion criteria. As opposed to Hansen et al., I excluded studies which did not focus on individuals' experiences of accessing EIS (such as, Bjornestad et al., 2016). In the case of Bjornestad et al. (2016), this paper investigated processes that "facilitated recovery from FEP [first episode psychosis]" (p. 141) with no focus on experiences of accessing EIS. Although some overlapping themes were present in that study and the present meta-synthesis, such as recovery processes, themes in Bjornestad et al. (2016) did not appear to emerge from discussions about experiences of accessing EIS.   I also excluded studies which focused on a specific intervention within EIS (for example, Firth et al., 2016), the rationale for which was discussed in the Methods section of the meta-synthesis.

Overall, the findings of the present study and Hansen et al.'s review included similar themes relating to people's experiences of EIS, such as the importance of

relationships, stigma, medication, identity, and hope. However, the research questions of

the two studies were slightly different, leading to overlapping but different foci of the two

meta-syntheses. Hansen et al. focused more on experiences of individual recovery in the

context of accessing EIS. For example, themes about initial experiences of psychosis and

'coming to terms with' psychosis were developed in Hansen et al.'s analysis. In this way,

Hansen et al.'s review provides important insight into how individuals experience and

conceptualise recovery in relation to psychosis, and how EIS can play a role in this

process. On the other hand, the present review focused more on the process of individuals'

journeys through EIS. For example, themes were identified relating to engagement and

collaborative practice. In doing this, the present review developed a deeper understanding

of the key processes within EIS, and how these processes can be most helpful and valuable

to individuals.

Sensitivity Analysis

Following the critical appraisal process, no studies stood as a significantly poorer in

'quality' than any of the other studies and there were no studies which I would view to be

of "questionable merit" (Carroll & Booth, 2015, p. 152). Although there were criteria

within the Kitto et al. (2008) tool which the studies did not meet, these were common

across all or most of the studies. In terms of conflicts of interest, it was often difficult to

ascertain the relationship between the researcher and the EIS and individuals who were

involved in the research. However, 'disconfirming cases' were presented in all but one

study (O'Toole et al., 2004) and the results did not appear to be overly one-sided in this

way. All 11 studies contributed to the four themes; no studies contributed

disproportionately to the analysis.

Strengths and Limitations

A strength of this review was that it highlighted the aspects of EIS which were experienced as helpful and important, as well as less helpful, from the perspectives of individuals for whom EIS are designed to support. This review also contributed to the limited systematic reviews of individuals' experiences of mental health services more generally. This meta-ethnography also included a third-order synthesis which both represented and went beyond the findings of the individual included studies. The chosen method of critical appraisal provided more detail about the decisions and process behind the appraisal compared to checklists which require a 'yes or no' answer, such as the widely used CASP tool. It was hoped that this increased the transparency of this review, enabling readers to criticise the processes and findings.

In terms of limitations, the majority of this meta-ethnography was conducted by a single person. However, the analysis was discussed with and checked by two experienced researchers. It is also possible that studies were missed during the search process, particularly given the previously noted difficulties extracting qualitative literature from databases (Barroso et al., 2003). Grey literature was excluded from the search strategy, however no relevant 'grey' studies are known to the author. It is unclear what contribution this research would have made to the findings. It is important to note that meta-ethnographies do not strive to provide a comprehensive summary of a research topic, but rather to develop a new interpretation (Doyle, 2003). Although the meta-ethnography aimed to garner an international perspective, the majority of studies were conducted in a single country, namely in the UK, within NHS services. However, the second-order concepts were very similar between countries, especially in relation to the first two themes.

This commonality across services and countries fits with a previous meta-ethnography (Stapleton & Wright, 2017). It is also important to note that, at least in terms of topic, this review duplicates that conducted by Hansen et al. (2018). It is unlikely that I would have conducted this review if Hansen et al.'s review was published earlier. Despite this however, the two meta-syntheses both contribute valuable and unique insight into individuals' experiences within EIS.

Generalisability

In qualitative research, generalisability is often used refer to how the findings might be relevant and transferable to other similar contexts. Qualitative researchers also talk about conceptual or theoretical generalisability, by which the conceptual understandings developed through the findings might be relevant to other humans and contexts. This contrasts with a quantitative account of sample generalisability, which seeks to collect data which closely reflects a wider population (Finlay, 2006). Within meta-ethnographies, conceptual generalisability is said to be achieved through the development of third-order syntheses which create a new understanding of a phenomenon (Noblit & Hare, 1988). By synthesising findings from 11 studies conducted across numerous EIS, it is hoped that the conceptual map developed here achieved this level of conceptual generalisability, allowing the findings to be transferred to other EIS.

It is also worth considering the relevance of the findings to other types of mental health services. Although there may be differences between EI and other mental health services, the majority of findings and themes appear to be relevant to any mental health service, an assertion which is supported by previous research. In this way, the conceptual generalisability of this meta-ethnography across mental health service contexts appears to

be quite high (Kitto et al., 2008). However, it is ultimately up to the reader to decide upon the relevance of these findings to their own context (Finfgeld-Connett, 2010).

The Author's Place in the Text

I provide here a brief description of my own 'place in the text' (Doyle, 2003). That is, the personal views and biases which have influenced my interpretations within this meta-ethnography. At the time of completing the analysis, I had no experience of working within an EIS so did not hold specific views about what 'should' happen in these services. I situate myself as holding a psychosocial, rather than biomedical, understanding of experiences labelled as 'psychosis'. This might have caused me to look for individual accounts, particularly negative ones, relating to biomedical understandings of 'psychosis' and its 'treatment' (that is, medication). I am also interested in the intended and unintended ways in which mental health services change people's views of themselves and their future. This personal interest might be reflected in the inclusion of concepts of stigma and identity relating to accessing EIS. The findings of this meta-ethnography are just one possible interpretation of individuals' experiences within the 11 included studies.

Clinical Implications

Based on the findings of this review, a number of clinical recommendations have been made. First, EI staff and services should place an emphasis on building trusting relationships with individuals. Relationships represented the starting point and foundation upon which further EIS interventions and meaningful life changes were made. Second, EI staff should ask about and be respectful of an individual's cultural and spiritual beliefs, avoiding pathologising these as 'symptoms' of 'psychosis'. These beliefs should be incorporated into an individual's understanding of their experiences of 'psychosis' in a

collaborative and person-centred manner. Co-developing individualised understandings of

'psychosis' was found to improve individuals' experiences of and engagement with EIS.

Third, although individuals seemed to value having the support of EIS, they also valued

moving on from the service. Individual care plans should be developed collaboratively to

include psychosocial and pharmacological interventions, but with an ongoing emphasis on

how these play a role in developing independence from EIS. Shared decision making over

aspects such as medication should be viewed not just as 'good practice' but as an important

part of the process of regaining agency, self-responsibility, and a sense of identity. Finally,

EI staff should also be aware of the inherent stigma associated with accessing an EIS, both

in terms of being in a 'specialist mental health service', as well as the stigma of 'needing

support' or having 'paid friends'. Professionals might consider explicitly discussing and

normalising this with individuals, similarly to how they might address stigma surrounding

'psychosis'.

Research Implications

Further studies should be conducted internationally so that ideas, knowledge, and

experiences can be shared to improve services in other countries. Even though five studies

came from a range of countries, namely Australia, Canada, Denmark, and the United

States, the majority (six) of studies in this review were conducted in the UK. However, the

major concepts and themes developed in this meta-synthesis appeared to extend across

studies conducted internationally. Future research should explore some of the tensions

which came out of this meta-ethnography. For example, the duality between independence

from and dependence on EIS and individuals' experiences of this. Feelings of agency and

responsibility were interpreted as important to this independence/dependence sub-theme;

this could be explored in more detail. Conducting research with individuals who are no longer accessing EIS, such as Lester et al. (2012), might provide a different, perhaps more holistic, perspective on accessing an EIS. It would also be interesting to look into individuals' experiences of developing an understanding of 'psychosis' with EI staff which incorporates personal, cultural, biomedical, and psychosocial frameworks.

Conclusion

This meta-ethnography synthesised 11 studies exploring individuals' experiences of accessing EIS. A conceptual map was developed to represent individuals' journeys through EIS. This included elements of EIS which were valued and contributed to individuals' feelings of hope, identity, and independence. Links between this meta-ethnography and other literature were made, with previous research supporting many of the interpretations. The findings led to a number of clinical recommendations for ensuring that EIS work in a collaborative and person-centred way, as well as recommendations for future research.

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Table 1.

Search Strategy for Databases.

'Early Intervention Service' search terms		'Qualitative research' search terms
"early intervention psychosis" OR "psychosis service" OR "early assessment and support" OR "first episode psychosis progra*" OR "early assessment services for young people with psychosis" OR "early treatment and identification of psychosis" OR "early psychosis".	AND	"thematic analysis" OR "grounded theory" OR "interpretative phenomenological" OR "focus group" OR "interview" OR "ethnograph*" OR "lived experience" OR "content analysis" OR "narrative*" OR "qualitative". OR (Additional search terms for each database, subject headings, thesaurus terms, etc. outlined below added to search here)

Note. Additional searches or changes to search

Academic Search Ultimate: Subject terms = 'qualitative research', 'qualitative research methodology'

CINAHL: CINAHL heading = 'qualitative studies'

EMBASE: Subject headings = 'qualitative analysis', 'qualitative research'

psycINFO: Thesaurus term = 'qualitative research'

PUBMED: MESH term: 'qualitative research'

SCOPUS = EIS terms searched in 'full text', Qualitative terms searched in 'Keywords, title, abstract' to limit number of articles retrieved as search results were significantly larger compared to other databases.

Web of Science: No 'full text' search available in this database. 'Topic' search completed instead.

Table 2.

Characteristics of Included Studies.

Study	Sample	Service context	Method of data collection	Type of analysis	Aim of study
Allard et al. (2016)	16 (5 female) aged 18-33. Current 'service users'	Multi-site. UK	Interviews (within [average] first 6 months of EI)	Thematic analysis	Service users' experiences of EIS across UK
Harris et al. (2012)	8 (3 female) aged 21-37. Current EI service users	NHS service. UK	Interviews	IPA	Service users' experiences of an EIS
Islam et al. (2015).	22 (11 female) aged 18-35. Current or past EI service users.	NHS service. UK	6 focus groups	Thematic analysis	BME service users' perception and experiences of EIS
Larsen (2007)	15 (no demographic information). Current EI service users.	Denmark	Repeated interviews	Person-centred ethnography	Service users' sociocultural processes in EI
Lester et al. (2011)	36 (10 female) aged 14-35. Current EI service users	Multi-site. UK	Interviews	Grounded theory	Service users' views of EIS across England
Lester et al. (2012)	21 (7 female) aged 18-33. Past EI service users	UK	Interviews	Grounded theory	Service users' experiences of moving on from EIS
Lucksted et al. (2015)	32 (11 female) aged <20 to 34. Current EI service users	Multi-site. USA	Interviews	Thematic analysis	Service users' views of engagement with EIS
O'Toole et al. (2004)	12 (4 female) aged 17-49. Current EI service users	UK	Focus group	IPA	Service users' experiences of an EIS
Stewart (2012)	30 (15 female) aged 18-20. Current EI service users	Australia	Interviews	Grounded theory	Service users' experiences of engagement during initial stages of EIS (first 6 months)
van Schalkwyk et al. (2015)	11 (1 female) aged 20-35. Current EI service users.	Urban community MH service. USA	Interviews	Thematic analysis	Investigate prolonged DUP before accessing EI and poor engagement after entry into EIS

| Windell & Norman (2012) | 30 (7 female) mean age 25.87. Current EI service users | Canada | Interviews | Thematic analysis | Examine factors that enhance or impede recovery from the perspective of individuals within EIS |

Notes. BME = black and minority ethnic, DUP = duration of untreated psychosis, EI = early intervention, EIS = early intervention service(s), IPA = interpretative phenomenological analysis, NHS = National Health Service, UK = United Kingdom, USA = United States of America

Table 3.

First- and Second-Order Constructs

		Allard et al. (2016)	Harris et al. (2012)	Islam et al. (2015)	Larsen (2007)	Lester et al. (2011)	Lester et al. (2012)	Lucksted et al. (2015)	O'Toole et al. (2004)	Stewart (2012)	van Schalkwyk et al. (2004)	Windell &Norman (2012)
Theme 1: Understanding through relationships												
	1.1: There to listen	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
	Importance of key worker or care coordinator relationship	X	X	X	X	X	X		X	X	X	X
	Always there to listen – staff as dependable and allowing individuals to feel heard	X		X	X		X	X	X	X	X	X
	Trust and opening up to EI staff; Difficulty with repeating life story		X	X	X	X	X	X		X		
	1.2: Explanations and understanding	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
	EI staff helped individual to understand psychosis through explanatory models	X	X	X	X	X	X		X	X	X	X
	Incorporating cultural and personal beliefs into explanatory model			X	X			X				

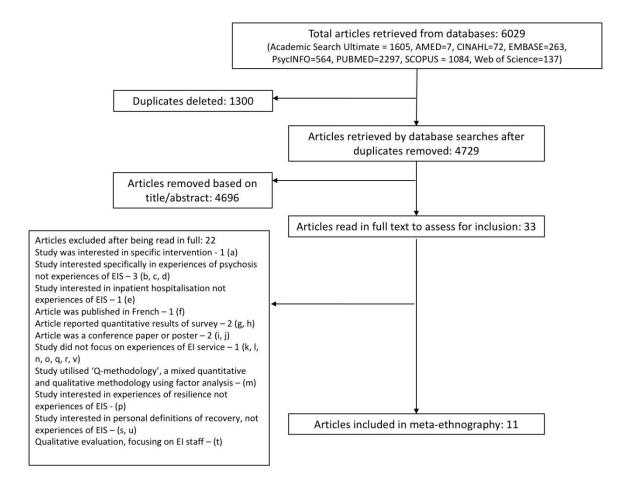|		Allard et al. (2016)	Harris et al. (2012)	Islam et al. (2015)	Larsen (2007)	Lester et al. (2011)	Lester et al. (2012)	Lucksted et al. (2015)	O'Toole et al. (2004)	Stewart (2012)	van Schalkwyk et al. (2004)	Windell &Norman (2012)
Theme 2: Recovery and hope												
	2.1 Practical support		**X**		**X**	**X**	**X**	**X**	**X**		**X**	**X**
	Individuals valued receiving support with employment, education, housing, finances, etc.		X		X	X	X	X	X		X	X
	2.2: Hope and the future	**X**	**X**	**X**	**X**		**X**	**X**	**X**	**X**	**X**	**X**
	Individuals' feelings of hope, on a continuum from hopeful and hopeless	X	X	X	X		X	X	X	X	X	X
Theme 3: Sense of self												
	3.1: Identity	**X**	**X**		**X**	**X**	**X**		**X**	**X**		
	Impact of EI on individuals' identity following experiences of psychosis	X	X		X	X	X		X	X		
	3.2: Independence/ Dependence	**X**	**X**		**X**		**X**		**X**			
	Individuals' experiences of moving towards independence	X	X		X		X		X			
	Individual feeling dependent on EI support						X					

		Allard et al. (2016)	Harris et al. (2012)	Islam et al. (2015)	Larsen (2007)	Lester et al. (2011)	Lester et al. (2012)	Lucksted et al. (2015)	O'Toole et al. (2004)	Stewart (2012)	van Schalkwyk et al. (2004)	Windell &Norman (2012)
	3.3: Feeling (ab)normal	**X**	**X**			**X**	**X**			**X**	**X**	**X**
	Experiences of stigma surrounding psychosis and accessing EI		X			X	X			X	X	X
	Feeling normalised through relationships with EI staff or other individuals	X	X							X	X	X
Theme 4: Medication			**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
	Medication managed collaboratively; helpful but not enough			X	X		X	X	X			X
	Individual felt coerced into taking medication		X								X	
	Weight gain from medication affected identity					X	X					
	Less focus on medication within EIS compared to inpatient setting									X		

Figure 1.

PRISMA Diagram for Inclusion of Studies.

Note. EI = Early Intervention; EIS = Early Intervention Service; a = Fisher & Savin-Baden (2001); b = Cadario et al. (2012); c = Judge, Estroff, Perkins, & Penn (2008); d = Uttinger et al. (2015); e = Fenton et al. (2014); f = Gauthier, Corin, & Rousseau (2008); g = McKenzie (2006); h = Morton, Fairhurst, & Ryan (2010); i = Greenwood et al. (2013); j = Tranulis & Bourque (2012); k = Hardy, Dickson, & Morrison (2009); l = Abarzúa, Venegas, & Hidalgo (2016); (m) = Barr, Ormrod, & Dudley (2015); (n) = Bay, Bjørnestad, Johannessen, Larsen, & Joa (2016); (o) = Grealish, Tai, Hunter, & Morrison (2013); (p) = Henderson & Cock (2015); (q) = Jansen, Wøldike, Haahr, & Simonsen (2015); (r) = Kapur et al. (2014); (s) = Lam et al. (2014); (t) = Callaly et al. (2010); (u) = Windell, Norman, & Malla (2012); (v) = Woodside, Krupa, & Pocock (2007)

Figure 2.

Critical Appraisal Tool.

2 Criteria for assessing qualitative research

Clarification
- What are the aims of the research?
- What is the research question?

Justification
- Why is a qualitative approach the best option to answer this question?
- Why was the particular qualitative research design chosen?

Procedural rigour
- Have the techniques of data collection been clearly documented?
- Are the forms of data analysis completely transparent?

Representativeness
- What sampling techniques have been used to answer the research question?
- Do the sampling techniques support conceptual generalisability?

Interpretation
- Has a more conceptual discussion of the results and linkage to existing theory or new theory been developed to explain the relevance of findings to a targeted audience or discipline?
- Have any negative cases been included and discussed?

Reflexivity and evaluative rigour
- Has a clear statement of the effect on the data of the researcher's views and the methods chosen been included?
- Has an explicit evaluation of the relationship between the researcher and those under research, addressing any ethical issues, been discussed?
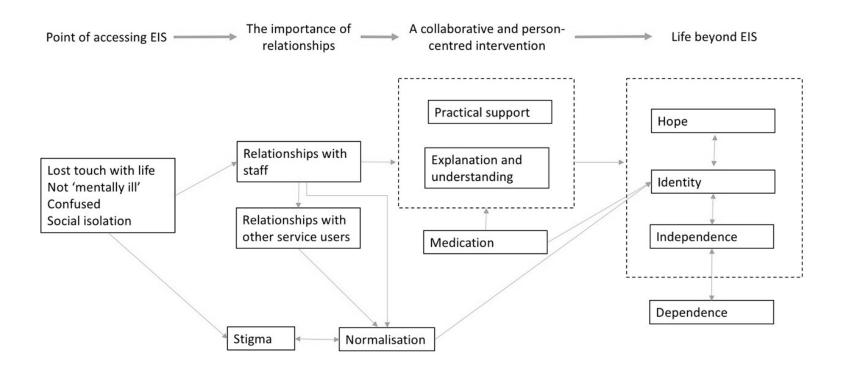- Has ethics approval been obtained from an appropriate institution?

Transferability
- Has a critical evaluation of the application of findings to other similar contexts been made?
- Has the relevance of these findings to current knowledge, policy, and practice or to current research been discussed?   ◆

Note. Taken from Kitto, Chesters, and Grbich (2008).

Figure 3.

Third-Order Synthesis of Meta-Ethnography

Appendix 1-A

Outcome of Critical Appraisal Process

	Allard et al. (2016)	Harris et al. (2011)	Islam et al. (2015)	Larsen (2007)	Lester et al. (2011)	Lester et al. (2012)	Lucksted et al. (2015)	O'Toole et al. (2004)	Stewart (2012)	Van Schalkwyk et al. (2015)	Windell & Norman (2012)
Clarification											
What are the aims of the research?	To explore carers' and service users' experiences of UK Early Intervention Services following referral for first-episode psychosis	To explore service users' experiences of being in contact with an EIP service, its impact on their experience of psychosis and current life situation.	To examine the cultural appropriateness, accessibility, and acceptability of an EIP service.	To discuss the value of a social science perspective of interpretative understanding and existential phenomenology to study sociocultural processes in a complex intervention, in particular when taking an ethnographic approach.	To explore service users' evolving experiences of EIP service, particularly their relationships.	To explore service users' perspective of EIP services and primary care, in-depth and over time.	To assess factors that facilitated or impeded clients' engagement in services offered by an EIP service.	To explore service users' experiences of a first episode intervention designed along evidence-based 'best practice' guidelines and to establish specific elements seen as effective to help inform future service planning and provision.	To describe how young people who had successfully engaged in treatment for a first episode of psychosis experienced the process of engagement during the initial stages of treatment.	To explore two major challenges in providing early intervention for psychotic illnesses: prolonged DUP before and poor engagement after entry into treatment.	To examine factors that enhance or impede recovery from the perspective of individuals receiving specialized EI care following their first episode of psychosis
What is the research question?	Not explicitly stated.	Not explicitly state.	How easily reached and suitable are EIP services for the ethnic and cultural needs of BME communities in Birmingham? How can these be improved?	Not explicitly stated.	Not explicitly stated.	Not explicitly stated.	Not explicitly stated.	Not explicitly stated.	How do these young people successfully engage despite the significant number of their peers who avoid or leave treatment prematurely? What enables the process of engagement?	Not explicitly stated.	Not explicitly stated.

Justification											
Why is a qualitative approach the best option to answer this question?	To inform process of putting 'information sharing partnerships' into practice within EI services	To explore service users' experiences of an EIP service.	Qualitative approach was chosen as it has the potential to provide rich data that reveal beliefs, needs, and preferences in health care.	Investigate the interpersonal dynamics of EIP service, processes which are crucial to effectiveness of an intervention.	To explore experiences and views of service users.	To explore experiences and perspectives of service users.	Not specified.	Experiential evidence essential for a service evaluation to be meaningful and complete.	Not specified.	Not much detail given – to supplement traditional research approaches.	Qualitative methods better able to explore determinants and contexts of recovery.
Why was the particular qualitative research design chosen?	Thematic analysis drawing on grounded theory and IPA. No reason given.	IPA chosen as study was interested in exploring personal meaning attached to experiences of accessing EIP service.	Interpretative design (thematic analysis) aiming to explore the experience and understanding of service users.	Ethnography – significant detail given on rationale.	Longitudinal design – to explore how experiences evolved over time. Grounded theory chosen but no reason given.	Longitudinal design – to explore how experiences evolved over time. Grounded theory chosen but no reason given.	Thematic analysis – no reason given.	Description of IPA given but no rationale.	Grounded theory provided a systematic way to identify and assemble the relevant themes relevant to the process of engagement. Further detail also given.	Thematic analysis – no rationale given.	Thematic analysis – no rationale given.
Procedural Rigour											
Have the techniques of data collection been clearly	Information about service context, recruitment, interview process in Lester (2011).	Information about service context, recruitment, consent. Length of interview, purpose of	Information about service context, recruitment process, 10% of people contacted refused (no	Yes – information given on context, recruitment, interviews, multiple means	Information about service context, recruitment, interview process.	Information about service context, recruitment, interview process.	Information about service context, recruitment, interview process, key topics in interview.	Information about service context, social context of catchment area, recruitment, interview/focu	Information about service context, recruitment, interview process. Some information on topic guide.	Information about recruitment, service context, interview questions.	Information about recruitment, service context. No information on topic guide.

documented?		interview, no interview schedule provided.	reason given by researcher), key questions in topic guide provided.	of collecting data.				s group process. No information on topic guide.			
Are the forms of data analysis clearly transparent?	Yes.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Representativeness											
What sampling techniques have been used to answer the research question?	Maximum variation sampling strategy.	Purposive sampling, service users with most time in EI service approached first. Participants who would require translator excluded.	Purposive sampling. Participants recruited through service managers/staff.	Researcher embedded in the EIP service.	Maximum variation sampling strategy.	Maximum variation sampling strategy.	Purposive sampling – clients we were deemed 'well engaged' and 'not well engaged'; clients who were new to service and clients who had been in service for longer period.	All SUs in service asked if they wanted to participate in research.	Researcher embedded in the EIPS service. Participants recruited via letters. 32 out of 40 people contacted nominated themselves to take part.	Participants recruited through service staff	Participants recruited through a larger study.
Do the sampling techniques support conceptual generalisability?	Majority of participants under 30 and from a specific UK county.	Recruited from one EIP service. Recruited by EI staff member who they had relationship with. Wide age range (21-37).	Recruited from one EIP service. Participants primarily from two particular ethnic backgrounds. No distinction between culture and ethnicity made.	No – but researcher explicitly states that this is not an aim of the research. No information on participants given.	Participants across 5 sites. Attrition between first and second interviews, not clear why.	Participants across 5 sites.	Range of participants sought, diversity across social/cultural demographics.	Participants who took part did not differ on demographic variables compared to those who did not. Diverse group of participants.	Diverse group of participants. Wide range of prior experiences with mental health services. Equal males and females. Narrow age range (18-20).	Only one female participant, recruited from one EIP service, unable to interview people who had disengaged from service.	Recruited from one EIP service. 90% of approached people agreed to be interviewed.

Interpretation											
Has a more conceptual discussion of the results and linkage to existing theory or new theory been developed to explain the relevance of findings to a targeted audience or discipline?	Analysis cross-checked among three researchers. Not specified if findings taken back to participants. No linkage to previous research or theory.	Analysis conducted by single researcher, no cross-checking. No participant validation mentioned. Links to previous research and theory made.	Analysis cross checked between members of research team and focus group facilitator. No participant validation mentioned. Links to previous research and theory made.	Analysis conducted solely by researcher. Links to previous research and theory made.	Analysis conducted by multiple members of research team. No participant validation mentioned. Links to previous research made.	Analysis conducted by multiple members of research team. No participant validation mentioned. Links to previous research made.	Analysis conducted by multiple researchers. No participant validation mentioned. Links to previous research made.	Analysis conducted by a single person. No participant validation mentioned.	Analysis conducted solely by researcher. No participant validation mentioned. Links to previous research made.	Analysis conducted by two researchers. No participant validation mentioned. Links to previous research made.	Analysis cross checked between two members of research team. No participant validation mentioned. Links to previous research made.
Have any negative cases been included and discussed?	Yes - Brief mention of two negative cases, but no quotes or interpretation offered.	Yes	Yes	Yes – Briefly described.	Yes – Briefly discussed. Disconfirming cases actively sought throughout.	Yes – Briefly discussed. Disconfirming cases actively sought throughout.	Yes	No.	Negative cases relating to other mental health services but not relating to EIS.	Yes	Yes – No negative cases relating to EIS experiences though.
Reflexivity and evaluative rigour?											
Has a clear statement	No.	Yes –The researcher considered	No	Yes	No.	No.	No.	No.	Yes –The researcher considered	No.	No.

of the effect on the data of the researcher's views and the methods chosen been included?		own views but not what these views were.								own views but not what these views were.		
Has an explicit evaluation of the relationship between the researcher and those under research, addressing any ethical issues, been discussed?	No.	Yes – discussion of recruitment by staff members.	No	Yes – but no ethical issues discussed.	No.	No.	No.	No.	Yes – discussion of dual role of clinician within EIS and researcher.	No.	No.
Has the ethics approval been obtained from an appropriate institution?	Yes – from NHS ethics committee.	Yes – from NHS ethics committee.	Yes – NHS ethics committee. Informed consent discussed.	Not specified	Yes – NHS ethics committee.	Yes	Not specified	Not specified.	Yes	Yes	Yes

Transfer ability											
Has a critical evaluation of the application of findings to other similar contexts been made?	Yes – discussion about age of participants and how the findings may relate differently to adults over 30.	Yes – brief discussion about applicability to other service users.	Yes – discussion about applicability of findings to other cultures/ethnicities made.	Researcher explicitly stated that generalisability not an aim of research.	No – application of results to other services made but not a critical discussion.	Yes – Discussion of how findings are less applicable to ethnic minorities.	Yes – Very brief	Yes- Briefly	Yes - Discussion about applicability to other services and people.	Yes – Briefly.	No
Has the relevance of these findings to current knowledge, policy, and practice or to current research been discussed?	Yes –To NICE guidelines. Research and practice implications made.	Yes – Brief practical and research implications made. Links to Mental Health Act.	Yes – Practical implications and recommendations made. No links to policy.	Yes – some research and practical implications provided.	Yes – practical and research recommendations made. Relationship to policy made.	Yes – practical, research, and policy implications made.	No specific practical, research, or policy implications made.	Yes – practical and research implications made. However, as findings were consistently positive no recommendations were made.	Yes – some research and practical implications provided.	Yes – some research implications made.	Yes – some practical implications made.

Appendix 1-B

Example of How One Included Study (Harris et al., 2012) was

Deconstructed as Part of Analysis

	Second-order concepts		First-order concepts	
Super-ordinate themes	**Sub-themes**	**Pertinent author interpretations and quotes**	**Pertinent participant quotes**	**My own initial themes and concepts**
Stigma	Self-stigma	"Rich accounts of personal shame and self-judgement" (p.460)		
		"Psychosis was deemed to be more serious and shameful than other diagnoses" (p. 460)	"I had psychosis, so I didn't like that. I mean depression's fine with me, but having psychosis isn't" (p.460)	
		Participants' inability to talk to others about psychosis (p. 460)		Stigma about psychosis
	Others' judgements	"participants' personal feelings of shame and the judgments made by other…creating a barrier to the EIP service" (p.460)		
	Stigma of services	Stigma surrounding mental health services and EIP (p. 461)		
		"distinction between mainstream services and EIP" (p. 461)	"I feel as though it's some kind of little special group that needs to be taken aside cus they need that extra remedial lesson type thing" (p.461)	Stigma about mental health services/EIP
		"powerful impact of the EIP service approach on reducing the stigma associated with mental health services" (p.461)	"that's what EIP kind of does, it softens that relationship between mental health authority and the punters" (p. 461)	
Relationships	Peer-support	Role of peer support in reducing isolation (p. 461)		Importance of relationships
		"relationships developed in the groups provided an opportunity to feel understood and created a		Feeling understood

		sense of belonging" (p. 461)		
		Peer support important in overcoming stigma (p.462)		Stigma
		Peer support an opportunity to help others (p.462)	"People tell you what their illness is and what kind of, then you try to come up with something that will help them and they do it vice versa to you" (p. 462)	Mutual peer support
	Care coordinator relationships	"the importance of the relationship between participants and care coordinators, on the participants' views of the EIP service" (p. 462)		Staff relationships
		Developing trust in care coordinator extended to participants trusting other people and interventions within EIP (p. 462)		Trust in EIS
Understanding the experiences		"participants' attempts to understand their experiences of psychosis and how it was influenced by their involvement with the EIP service" (p. 462)		Understanding of psychosis
		EIP provided participants with information, normalisation, and sense of hope (p. 463)		Normalisation
				Hope
		EIP "provided them with information about psychosis and their first sense of relief and optimism about their future" (p. 463)	"they just told me that the fact was, there are other people like you and you can get better from it…yeah and that just, relief really and like before I just thought I never, OK the rest of my life not getting better" (p. 463)	Understanding of psychosis
				Hope
		"participants were able to form their own personal frameworks for understanding, beyond those offered by the service" (p. 463)		Understanding of psychosis

Sense of agency	Acceptance and control	"Participants' accounts were interpreted as representing a shift from an initial avoidance of acknowledging their experiences, towards an acceptance of their presence" (p. 463	"Sort of living with my symptoms and dealing with it, accepting it" (p. 463)	Recovery
		"other participants described a sense of active control over their experiences, which was supported by the EIP service" (p. 464)		Agency
		Views of psychosis and symptoms influenced by relationships with care coordinator (p. 464)		Staff relationships
		Participants "recognized their own role and the importance of personal responsibility for their future" (p. 464)	"there is no one who can actually provide the solution, other than yourself (p. 464)	Agency
	EIP service involvement	"participants were offered limited options regarding treatments, with medication being the predominant or sole choice" (p. 464)		Medication
		Participants experienced both being in control of treatment, and not being in control (p. 464)	"It feels as though . . . everything is being taken out of your hands and you just…feel worthless really" (p. 464)	Collaborative approach to interventions
Impact on sense of self	A sense of discovery	"participants' experiences of discovering a new and stronger self" (p. 465)	"I'm stronger now than I ever was" (p. 465)	Identity
		"EIP service had helped them to identify positive changes in themselves" (p. 465)		Identity
	Place within the world"	"many participants had experienced dramatic changes in their lives, resulting in feelings of a detachment from their previous world" (p. 465)		Sense of self
		Role of EIP providing support with employment and social aspects of life (p. 465)		Practical support

		"some participants described a deeper and ongoing sense of detachment from their world" (p. 465)	"all the psychotic people are operating on the same frequency and all the people outside of that are operating on another frequency" (p. 465)	Sense of self
				Stigma
		Sense of "incompatibility with the world" (p. 466)		Sense of self
A personal journey of discovery		"Moving beyond symptom alleviation" (p. 466)		Recovery
		Recovery a complex process, but was positively influenced by EIP (p. 466)		Recovery
		Relationships with others (care coordinators and peers) fostered hope (p. 467)		Relationships
				Hope

Appendix 1-C

Example of How the Themes and Sub-themes were Developed

Based on the Included Studies

Examples of themes and concepts from studies	My own initial concepts	Sub-themes	Super-ordinate theme
Staff adopted position of 'warm respect' - Lucksted et al. (2015)	Stance of EI staff	Subtheme 1.1: 'There to listen': Importance of relationships	Theme 1: Understanding through relationships
Genuine care, personal investment, and respect – Windell & Norman (2012)	Stance of EI staff		
Feeling listened to, understood, and cared for/loved – O'Toole et al. (2004)	Being heard		
Staff continuity - Repeating details of life story - "traumatic" – Islam et al. (2015)	Continuity of relationships		
'Key workers and insight' – Major theme in Allard et al. (2016)	Developing an understanding of psychosis	Subtheme 1.2: Explanations and understanding	Theme 1: Understanding through relationships
EI staff combined biomedical with cultural/religious explanations to provide "individually satisfying explanatory models" – Larsen (2007)	Drawing on multiple explanatory models – person centred.		
Opening up about experiences helped service user to understand their experiences – Allard et al. (2016)	Relationship facilitated better understanding of experiences		

Appendix 1-

Explanation of How Themes and Sub-themes 'Map Onto' the

Third Order Synthesis (see Figure 3)

Stage 0: Point of accessing EIS	Stage 1: The importance of relationships	Stage 2: A collaborative and person-centred intervention	Stage 3: Life beyond EIS
Sub-theme 1.1: 'There to listen': Importance of relationships	Sub-theme 1.1: 'There to listen': Importance of relationships	Sub-theme 2.1: Practical support	Sub-theme 2.2: Hope and the future
		Sub-theme 1.2: Explanations and understandings	Sub-theme 3.1: Identity
Sub-theme 1.2: Explanations and understandings	Sub-theme 1.2: Explanations and understandings		
			Sub-theme 3.2: Independence/ dependence
Sub-theme 2.1: Practical support	Sub-theme 3.3: Stigma and normalisation	Theme 4: Medication	
Sub-theme 3.3: Stigma and normalisation			

Appendix 1-E

Journal of Psychosocial Rehabilitation author guidelines

Retrieved from: http://www.psychosocial.com/pub.html#HEAD1B

Standards & Submission Guidelines

Content: This peer reviewed Journal is dedicated to the continuing development and ongoing evaluation of psychosocial rehabilitation, ACT programs and therapeutic techniques. As such, all articles remotely pertaining to such treatment will be considered for publication. However, the International Journal of Psychosocial Rehabilitation reserves the right to reject any and all articles, but will only do so in cases in which article content does not apply to the goals of the Journal.

Style: Though this journal maintains the publication standards set forth in the American Psychological Association's Publication Manual, we also recognize this may not be available to all practitioners throughout the world. We therefore view the manual as guidelines and not religious canon. Do your best to comply with the style manual, but submit your material anyway.

Editing: In keeping with the spirit of free speech across the internet, the materials presented for publication will not be edited beyond simple conversion to HTML format and presentation layout. It is therefore in your best interest to REALLY EDIT YOUR MATERIAL WELL. It will probably be published as submitted.

Format: All articles for consideration must be submitted in text, DOS text, hypertext or Word for Windows 'doc' format; transmitted in text, binary, or mime format. All Tables and Figures must be submitted in either Hypertext, Word for Windows 'Doc' format, GIF or JPEG files. There can be no exceptions to this policy as the technology for graphic insertion is limited. There are no size limitation on articles.

Preparing the Manuscript

Target Audience: mental health care professionals, applied researchers and service users in mental health or substance misuse programs

Length: Flexible, ranging from 1000 to 10,000words (10 to 20 double-spaced, typed pages), plus photos, charts, tables, and illustrations. Subjects that require extended treatment may be presented as a series (i.e., Part I, Part II).

Organization: Where possible, articles presenting original data should be organized using standard scientific sections and subheadings: Introduction, Materials and Methods, Results, and Discussion. For articles in which these headings are not appropriate, such as review articles, descriptive subheadings should be provided to clarify the article's content.

Reviews and other types of articles may be organized in a similar manner. For example, the introduction to a review article could describe the number of studies reviewed and the basic conclusions reached.

<div align="center">Essential Elements of a Manuscript</div>

Author Responsibilities: It is required that all authors who (including every author of a multiauthored article):
Guarantee their sufficient participation in the planning, design, analysis, interpretation, writing, revising, and approval of the manuscript.

 Disclose any and all financial information relevant to the article.

Every manuscript should contain the following elements, each beginning on a new page:
Title page
Abstract and keywords
References
Tables and Illustrations
Title Page: The title should be concise and informative. Authors should be listed by first name, middle initial, last name, and degree(s). A primary academic title and department affiliation should be provided for each author. Give the name, mailing address, and email address of the author responsible for correspondence.

 Abstract and Keywords: The abstract, structured or unstructured as appropriate, should highlight the significant content of the article. A list of 3 to 5 keywords should be provided beneath the abstract for use by indexing and abstracting services.
manuscripts should be accompanied by an unstructured abstract of up to 150 words. Unstructured abstracts should address the objective, main points, and conclusion of the article. Abstracts are not required for editorials, commentaries, policy papers, book reviews, or special features.

References: References should be listed in alphabetical order. Use APA style for references Please remove all auto-formatting and automatic reference numbering from the final document.

Captions: Captions for graphics or other supplemental material should be no more than 50 words. Include magnification, stain, and other pertinent data where applicable.

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Section Two: Empirical Paper

Experiences of individuals with a biological parent with experiences of 'psychosis' or a diagnosis of 'schizophrenia'

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Abstract

Previous research has demonstrated familial patterns of mental health difficulties. These findings are accounted for by two main explanations: that mental health difficulties have a strong biogenetic component, or that these patterns can be attributed to intergenerational psychosocial factors. This study explored the impact of biogenetic and psychosocial explanations for mental health difficulties on the children of people who have experienced 'psychosis' or received a diagnosis of 'schizophrenia'. Four participants took part in a semi-structured interview. Interpretative Phenomenological Analysis was adopted as a methodology. Four super-ordinate themes were developed: (1) The Fear; (2) Signs of (in)sanity - Navigating my own mental health; (3) 'Who is my mum?' - Multiple and evolving identities, relationships, and (re)connection; (4) 'A caregiver for your caregiver' - Multiple family roles and responsibilities. These themes were linked to previous research and theory. Clinical recommendations for professionals and ideas for future research were made.

Keywords: psychosis, schizophrenia, family mental health, interpretative phenomenological analysis

Numerous studies have found that a person is more likely to receive a psychiatric diagnosis if they have one or more family members who have also been given a diagnosis (e.g. Berrettini, 2000; Sullivan, Neale, & Kendler, 2000). This research has been summarised colloquially as: 'mental illness runs in families', an axiom which has made its way into the public discourse through information provided by the National Health Service (NHS) and major mental health charities in the United Kingdom (UK) (NHS, 2015, 2016d; Rethink Mental Illness, September 2017). However, there is considerable debate over exactly *why* members of the same family are more likely to be given a psychiatric diagnosis. One side of this debate views this as the result of intergenerational psychosocial factors, such as poverty, discrimination, and trauma (Hudson, 2005; Johnstone, 2000). The other viewpoint sees psychiatric diagnosis as reflecting an underlying 'mental illness' with some degree of heritability, which is associated with neurobiological changes and 'triggered' by environmental and social factors (Yank, Bentley, & Hargrove, 1993). This biogenetic account of psychological distress, sometimes referred to as the 'biomedical model', has become the predominant model within mental health services in the UK, features heavily in publicly available mental health information, and is arguably the dominant understanding in the UK and most other Westernised societies (Harrington, 2012). Regardless of which ideological standpoint one takes, being a person who has a family member who has experienced mental health difficulties clearly has implications for your own mental health 'risk' – whether this is through your environment, your upbringing, or your genes. This study explored the impact of psychosocial and biogenetic accounts of psychological distress/'mental illness' on the family members of people who have experienced mental health difficulties, and specifically on children.

Public Explanatory Models of Psychological Distress

As mentioned, the notion of 'familial mental illness' can be explained through biogenetic or psychosocial accounts, with these often being combined in the form of 'vulnerability-stress' models (Yank et al., 1993). In order to better understand how these models might impact on families, it is worth investigating how people living in Westernised societies conceptualise the causes of mental health difficulties. Previous research indicates that members of the public are more likely to cite environmental stressors and life events as causing 'mental illness' rather than biogenetic factors (Dietrich et al., 2004; Read & Law, 1999). However, a more recent review indicates that publicly held views may be shifting towards viewing biogenetic factors as the main cause of mental health difficulties (Schomerus et al., 2012).

Providing one explanation for this trend, emphasising the biogenetic elements of psychological distress has been a campaign focus of mental health organisations and charities both in the UK and internationally (Albee & Joffe, 2004; Pescosolido et al., 2010). The aim of these campaigns (for example, Like Minds Like Mine, 2003) has been to address stigma by reducing individual responsibility for 'mental illness' – that a person's brain is to blame (Rüsch, Todd, Bodenhausen, & Corrigan, 2010). Unfortunately, it appears that these stigma-reduction campaigns have not significantly improved public attitudes towards people with psychiatric diagnoses, and there is even research showing that they have *increased* social stigma and discrimination towards people labelled as 'mentally ill' (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Read, Haslam, Sayce, & Davies, 2006). As a result of these campaigns, and wider societal trends towards viewing science and technology as solutions to mental health difficulties (see Thomas et

al., 2005), biogenetic explanations of mental health difficulties have been placed squarely into the public consciousness and made available to individuals and families experiencing mental health difficulties.

As an indication of this, previous research has found that family members of people with experiences of 'psychosis' attributed their relative's mental health difficulties primarily to neurobiological and genetic causes (Esterberg & Compton, 2005). Similarly, Meiser et al. (2007) explored the causal beliefs of family members of people who had received a diagnosis of 'bipolar disorder', with biogenetic explanations again being the most commonly cited by participants. In addition to the public trend towards biogenetic explanations for 'mental illness', these findings could also result from families being more likely to be given, and seek out, information about 'mental illness'; information which increasingly favours biogenetic accounts (Schomerus et al., 2012). For example, biogenetic explanations feature on the NHS Choices website, the top UK Google result for searches of 'schizophrenia', 'bipolar disorder', and 'borderline personality disorder' as of 5th May 2018 (NHS, 2015, 2016a, 2016d). In contrast to this, other research with family members of individuals with a diagnosis of 'schizophrenia' found that relatives were more likely to cite psychosocial factors as a cause of 'schizophrenia' (Magliano, Fiorillo, De Rosa, Malangone, & Maj, 2004; Read & Magliano, 2012). Overall, research has yielded mixed findings in terms of whether families have a preference for psychosocial versus biogenetic explanations, and it appears that family members hold a combination of these in making sense of their relative's mental health difficulties. However, relatives of individuals who receive psychiatric diagnoses are undoubtedly aware of biogenetic accounts of mental health difficulties, even if they choose not to adopt them.

The Impact of Biogenetic Accounts

Much of the literature looking at the impact of psychiatric diagnoses has focused on the experiences of the individuals who receive these labels. Viewing psychological distress as a primarily biogenetic 'mental illness' has important implications for people who receive a psychiatric diagnosis. It can lead diagnosed individuals to view their 'illness' as a defining and permanent feature of their identity, one associated with shame and a sense of being abnormal as a person (Rüsch et al., 2010). However, biogenetic accounts also appear to hold a helpful function in providing both the diagnosed individual and their family with an explanation for the individual's difficulties (Cooklin, 2010; Easter, 2012).

The biogenetic, and thus hereditary, aspect of the biomedical model also has specific implications for families in terms of the causes of 'mental illness'. For example, a parent of a child who has received a psychiatric diagnosis may find it easier to attribute their child's mental health difficulties to 'faulty genes' rather than to their parenting ability or the home environment. Indeed, research suggests that biogenetic explanations can alleviate (but not dissolve) some of the guilt, blame, and responsibility experienced by parents who have a child diagnosed with a 'mental illness' (Callard et al., 2012). Although the biomedical model appears helpful for parents in this respect, genetic accounts could have harmful implications for relatives of individuals diagnosed with a 'mental illness', with the biggest impact being on children (Phelan, 2005). That is, having a parent with a 'mental illness' might mean you are likely to have this 'illness' passed on to you; that you are in possession of a genetic 'ticking time bomb'. Qualitative research with adolescents with a parent diagnosed with a 'mental illness' lends support to these concerns (Davison &

Scott, 2017). In a study with siblings of people who had received a diagnosis of

'schizophrenia', the majority of participants feared inheriting the family 'mental illness'

and worried about their own psychological wellbeing (Stålberg, Ekerwald, & Hultman,

2004). Overall, mentions of this concern within the research are brief and no known

studies have focused on exactly how biogenetic versus psychosocial explanations of

'mental illness'/psychological distress influence how children of parents with a mental

health diagnosis view and construct their own psychological wellbeing.

The Present Study

The present study was interested in the experiences of individuals with a biological

parent who had experienced 'psychosis' or received a diagnosis of 'schizophrenia'. This

study focused on 'psychosis' because it is often viewed as being 'caused' by biogenetic

factors (including both physical and 'mental' illnesses) (NHS, 2016b). 'Psychosis' refers

to experiences such as hearing voices, seeing things that other people do not, or holding

'unusual' beliefs (British Psychological Society, 2014). 'Psychosis' is sometimes

associated with the psychiatric diagnosis 'schizophrenia', as well as with 'bipolar disorder'

(NHS, 2015, 2016c).

Because of the messages about the heritability of 'mental illness' mentioned

previously, individuals who have a family member who has experienced

'psychosis/schizophrenia' may view themselves as 'at risk' of experiencing

'psychosis/schizophrenia'. In fact, the idea of inherited 'mental illness' is reflected in the

policies of NHS specialist mental health services for people experiencing 'psychosis'.

Early Intervention Services (EIS) can label individuals 'at risk of developing psychosis' if

they are experiencing 'a reduction in daily functioning' and if they have a first-degree

relative who has experienced 'psychosis' or received a diagnosis of 'schizophrenia' (NHS England, 2016). It could be argued that the widespread cultural messages about mental health difficulties, such as 'psychosis', running in families place an implicit 'at risk' label on individuals with a parent who has experienced 'psychosis', regardless of whether this label has been formally given by mental health services. There is some research looking at the impact of a formal 'at risk of developing psychosis' label (Corcoran, Malaspina, & Hercher, 2005; Welsh & Brown, 2013). However, there appears to be no published research into the experiences of individuals with a parent who has experienced 'psychosis' who do not access specialist mental health services, and specifically how their parent's mental health experiences have shaped their view of their own psychological wellbeing. Callard et al. (2012) conducted a similar qualitative study looking at how family members of individuals with a diagnosis 'schizophrenia' drew on genetic explanations. However, this study focused more on issues surrounding the 'passing down of schizophrenia' from parents to children.

The study aimed to address the research question: how do adults who have a biological parent who has experienced 'psychosis' or received a diagnosis of 'schizophrenia' view and make sense of their own psychological wellbeing? The study was especially interested in how these individuals draw on biological, genetic, and psychosocial explanations of 'psychosis/schizophrenia' in relation to their own psychological wellbeing. In order to explore these issues, Interpretative Phenomenological Analysis (IPA) was adopted as a methodological approach. IPA is a qualitative methodology which is interested in the experiences of individuals, and particularly in how people give meaning to these experiences by drawing on psychological and sociocultural

understandings (Larkin, Watts, & Clifton, 2006). Biggerstaff (2008) views IPA as

particularly suitable for studies interested in situating the findings in the context of

biological and psychosocial theories, a focus of the present study.

Method

Participants

Four people took part in the interviews which formed the data for this study. The

demographic information of these participants can be found in Table 1. Participants were

recruited via social media (Twitter/Facebook) and through contact with local organisations,

such as carer support and mental health charities. Initially, attempts were made to recruit

via regional specialist psychosis services, however this was not viable due to an already

high amount of research being conducted in the area. Instead, it was hoped that recruiting

via social media would increase the exposure of the study, opening it up to a wide range of

individuals both in the UK and internationally. Contact with local organisations was made

in an attempt to develop face-to-face links with members of staff who might pass on the

details of the study to any relevant individuals.

Inclusion criteria for participants were: aged 18 and over; had one or both

biological parent(s) who had experienced 'psychosis' or received a diagnosis of

'schizophrenia'; had not accessed a specialist 'psychosis' service themselves; and were not

accessing mental health services at the time of the interview. These inclusion criteria were

purposively designed to recruit a homogeneous sample of participants who shared similar

familial and personal experiences of mental health. Recruiting a homogeneous sample is

viewed as important in IPA in order to not only ensure that the research question is

relevant to all participants, but also to allow researchers to have greater confidence in

making claims about the theoretical generalisability of the findings to other people with similar experiences to the participants (Robinson, 2014; Smith & Osborn, 2004). Having a homogenous sample also allows researchers to explore the nuances of a research question, the similarities and differences among the individual participants, and provides a deeper understanding of a phenomenon (Smith, Flowers, & Larkin, 2009).

The target sample size for this study was six to eight participants (Smith, Larkin, & Flowers, 2009). However, recruitment was stopped at the point of recruiting four people due to not being able to recruit any further participants via the chosen recruitment strategy. At this point, I considered broadening the inclusion criteria for the study to include people who had accessed specialist psychosis services themselves. However, this risked the homogeneity of the sample, which the four participants appeared to possess across a number of demographic factors, such as age, geographic location, and their biological parent being their biological mother.

Silverman (2010) advocates for "theoretically informed flexibility" (p. 153) about sample size, which involves making decisions about sample size based on looking at the data as it is collected. Consequently, initial reading of the transcripts by myself and my supervisor indicated that the data would most likely be 'rich' enough in content and complexity to allow for a meaningful and interesting analysis with just four participants. In support of this decision, Smith, Flowers, and Larkin (2009) view depth and quality of data as more important than having a large sample. Furthermore, a smaller sample can mean that participants are able to retain their own 'voice' and identity within the study, without being amalgamated into a collective 'whole' (Robinson, 2014). At the same time however, ending recruitment prematurely prevented additional participants, and thus

experiences and perspectives, from being included in the analysis and findings. This might

have limited the generalisability of the findings to other people with similar experiences to

the participants. Further discussion of the recruited sample can be found in the

'methodological issues and research implications' section of this paper.

Procedure

Ethical approval was gained through the Lancaster University Faculty of Health

Medicine research ethics committee prior to recruitment. Potential participants were

provided with an information sheet and copy of the consent form to read prior to agreeing

to take part in the research. An appropriate location for the interview was then agreed

upon between myself and the participant. Three interviews took place face-to-face, one

interview was conducted over Skype. Participants gave written consent, or verbal (over

Skype) consent, prior to the interview. Participants were told that they would be given a

pseudonym to preserve anonymity. However, participants were able to choose their own

pseudonym so that they could more easily identify themselves in the findings. This

approach to anonymity was chosen as a 'safe enough' middle ground between protecting

the identity of participants and denying them an active voice in the research (Parker, 2005;

Reynolds, 2014). Participants took part in a semi-structured interview lasting between 40

and 90 minutes. At the start of the interview, I told participants that I had a family member

with a diagnosis of 'schizophrenia' which had an impact on me growing up, and that this

had motivated me to conduct this research. I wanted to avoid 'colouring' each

participant's views by sharing specific details of my own experiences prior to the interview

but I said that I would be willing to discuss my own experiences after the interview. This

degree of self-disclosure was planned as a way to "level the playing field" (Dickson-Swift,

James, Kippen, & Liamputtong, 2007, p. 332) between myself and participants, with the aim of increasing rapport and their degree of comfortableness in speaking openly about their experiences.

The topic guide for this interview was based on the research question and followed guidance provided in Smith, Flowers, and Larkin (2009). An individual with personal and family experiences of 'psychosis' acted as a consultant on the project and provided input on the topic guide, recruitment materials, and overall research process. The topic guide can be found in Appendix 4-F. Although the research was interested in biogenetic and psychosocial explanations of mental health difficulties, I did not introduce these topics into the conversation and followed participants' descriptions and understandings of mental health. All interviews were carried out by myself and were recorded using a digital recording device and transcribed verbatim by myself.

Analysis

The analysis followed the IPA process outlined in Smith, Flower, and Larkin (2009). As recommended by these authors, each transcript was analysed individually. Personal reflections and notes were kept in a diary during analysis so that I could become more aware of my own views and assumptions and aim to 'bracket' these off. I began the analysis process by familiarising myself with the data through multiple readings of each transcript and re-listening to the interviews. Initial notes were then made alongside the transcript relating to: the content of the interview; the words, metaphors, and tone used by the participant; and more abstract and conceptual ideas as interpreted by myself. I then developed emerging themes based on these initial notes, with a focus on creating themes at a more interpretative level than the initial comments. I then looked for connections

between these emerging themes in order to develop main themes for each transcript.

Supervision was sought following analysis of the first transcript. These steps were then

repeated for each transcript. Finally, the main themes and sub-themes across each

transcript were analysed together to look for points of similarity and difference to develop

the final set of 'super-ordinate themes'.

IPA places an emphasis on acknowledging the role of the researcher throughout the

research process. Like every researcher, I brought my own personal experiences, interests,

assumptions, and biases to this study. Specifically, having an uncle with a diagnosis of

'schizophrenia' I found the biogenetic narrative surrounding 'schizophrenia' unhelpful and

it led to concerns about my own psychological wellbeing. During the interview and

analysis processes I remained conscious of my experiences and views and attempted to

reflect on these to not only separate them from participants' experiences, but also to draw

on them in order to better make sense of the data (Eatough & Smith, 2008). I drew on

Eatough and Smith's (2008) notion of multilayered interpretation during the analysis

process, pushing to develop a number of possible interpretations of each participant's

experiences. In doing this, I was attempting to put into practice postmodern ideas of

multiple possible realities, rather than striving to 'discover' *the* correct interpretation (Nath,

2014). I also adopted a social constructionist epistemology when considering how

participants' experiences and associated meaning-making reflected sociocultural discourses

(Frost et al., 2010).

Trustworthiness and Transparency

The interpretations within the analysis were discussed in supervision between

myself and two research supervisors, this provided a means to check whether the analysis

was coherent and 'warrantable' (Biggerstaff & Thompson, 2008). Upon completion of the analysis, the findings were taken back to the participants, a process referred to as 'respondent validation' (Mays & Pope, 2000). This validation process was approached not as a means by which participants could 'correct' my own interpretations, but rather so that they could add their own comments and views on my analysis, which were then incorporated into the analysis (Mays & Pope, 2000). One participant (Sarah) responded to reading the analysis and did not have any comments. A clear 'decision trail' was kept throughout the analysis (Noble & Smith, 2015). Examples of how the themes were developed from the data are provided in Appendix 2-C as a means of ensuring transparency and accountability. Pertinent quotes from participants have been included in the findings to not only illustrate the themes, but to allow readers to judge whether my interpretations fit with the data (Mays & Pope, 2000).

Results and Discussion

Four super-ordinate themes were developed through the analysis process: (1) The Fear; (2) Signs of (in)sanity - Navigating my own mental health; (3) 'Who is my mum?' - Multiple and evolving identities, relationships, and (re)connection; (4) 'A caregiver for your caregiver' - Multiple family roles and responsibilities. Each of these super-ordinate themes included a number of sub-themes (Table 2).

Theme 1: The Fear

This super-ordinate theme documents participants' experiences of 'The Fear' of inheriting their parent's mental health difficulties. The sub-themes within this super-ordinate theme chart the process by which participants came to encounter The Fear and their personal journeys to escape or move beyond it.

Sub-theme 1.1: Knowing 'The Fear'. All participants described experiencing

The Fear at some point in their lives, to varying degrees. "I remember crying to my sister

'I'm going to be like mum'…I did think about it constantly...'It's going to happen to me,

it's going to happen to me'. It was just panic" (Leigh). For participants who grew up in

their biological families, there was a clear narrative within the family of hereditary 'mental

illness'. "There's a rich tapestry in the family, of mental [illness]" (Alex). This genetic

thread was described by other participants who cited numerous family members who had

experienced mental health difficulties, something which multiplied The Fear. It was not

just participants who came to know The Fear, it was felt and spoken about throughout the

family. 'Mental illness' appeared to have become spoken about like a family profession.

"Because it is in our family, in our blood" (Leigh).

In addition to being part of the family mental health narrative, The Fear was

sometimes encountered directly in a particular moment, such as through an interaction with

a mental health professional.

> I went and seen the psychiatrist with my dad and he said like, 'Oh has anyone in
>
> your family got any mental health issues?'…And then my dad told him [about their
>
> family history] and he was like 'Oh it's hereditary'. So I remember knowing from
>
> that day the fear of 'Oh my god this could happen to me'. (Leigh)

This quote, and the direct, "stern" (Leigh) way in which the psychiatrist spoke to Leigh,

fits with previous research indicating that mental health professionals who hold a strongly

biogenetic view are often less empathic and compassionate towards their clients (Lebowitz

& Ahn, 2014).

Other participants appeared to develop The Fear over time, perhaps through absorbing societal discourses or information in the media. Schomerus et al. (2012) argue that the information available to the general public has become increasingly biogenetic over the past decade. The Fear became heightened for all participants when they experienced a period of increased emotional distress; this was during their late teenage years and early 20's. Sarah was aware of information and research predicting an 'at risk period' between 15 and 35 for experiencing a 'first episode of psychosis' (Kessler et al., 2007; Rethink Mental Illness, n.d.), something which compounded The Fear and had her questioning whether "this is the beginning". Overall, this sub-theme supports the concerns raised by Phelan (2005) in terms of the negative impact of biogenetic accounts of mental health for children of people who receive psychiatric diagnoses. Participants' experiences also mirrored those expressed in previous research with people who have a relative with mental health difficulties (Davison & Scott, 2017; Riebschleger, 2004; Stålberg et al., 2004).

Sub-theme 1.2: Uncertainty about the certain. Discussions about The Fear were filled with references to both certainty and uncertainty, with these two positions often being held simultaneously. For participants, inheriting their parent's 'mental illness' was a *possibility* which was *definitely* in their genes. "I'd always kind of accepted that given the family history you know…it was just like, it might happen, and it did. So….there wasn't much I could do about it" (Alex). This mirrors findings from another similar study in which family members viewed 'schizophrenia' as an "inevitable yet unpredictable" entity within their family (Callard et al., 2012, p. 284). The relationship to and position within this certainty/uncertainty dialectic changed constantly over the course of each interview,

and indeed across each participant's life. The Fear also held multiple locations in relation to participants, sometimes lying within them, sometimes following them like a spectre, sometimes waiting ahead of them in their inevitable future. "The family tradition has come to haunt me too" (Alex); "So that is something that I feel like in my future kind of stalks me a little bit" (Niamh).

The Fear represented a certainty for participants, that it was their destiny to end up like their parent. For Sarah, this made her feel helpless, like a "pawn in this genetic game". This reflects genetic essentialist and deterministic ideas - that our genes reflect who we are as people and how we behave, mapping a set path through life (Phelan, 2005). Niamh echoed these concepts, viewing the potential of 'mental illness' as something which lurked inside her and influenced how she viewed herself.

At the same time, there was an element of uncertainty regarding when or how participants might become "mentally unwell" (Leigh). This uncertainty led to feelings of worry, confusion, panic, and seemed to convey a sense of impending doom. However, uncertainty also played a role in helping participants to move beyond The Fear; this will be discussed in the next sub-theme.

Sub-theme 1.3: Escaping 'The Fear'. Entertaining the uncertain and the possibility that they might not inherit their parent's 'mental illness' represented a starting point from which participants were able to move away from, and even escape, The Fear. This is reminiscent of Weingarten's (2010) concept of 'reasonable hope', which views an uncertain future as the exact condition within which hope can develop. In other words, it is only when participants did not view their lives as predetermined by genes, or fate, that they were able to envision possibilities which were in line with what they wanted from life.

All participants engaged in their own personal mission to develop alternative explanations about 'mental illness' other than biogenetic accounts. Some participants turned to their family, not only for reassurance, but for evidence that not becoming 'mentally ill' was possible and realistic. "I looked at my dad as well, like my dad's been around it…and he never has been…mentally unwell. So…I just think it can't be that definite" (Leigh). In this sense, participants were dealing with two levels of knowledge – 'expert knowledge' which presents 'mental illness' as hereditary, and 'local knowledge' (Besley, 2002) within their family that this genetic narrative could be overcome.

Participants also looked online for information about 'mental illness'. Previous research has found that family members can find it difficult to make sense of the complex, and often contradictory, information available (Sin, Moone, & Wellman, 2005). For Sarah, however, it was this wealth of mixed and contradictory information that created space for possibilities and alternatives to biogenetic accounts.

Interviewer: How did you get to that understanding of schizophrenia,

of…psychosocial understandings of distress?

Sarah: I think…reading a half baked Google article that said that it might be

genetics or it might not be, the jury's out, so I was like, 'OK so no one knows'.

As participants moved away from The Fear, they began to view their own mental health as being within their control. At times, participants even expressed feelings of shame and anger that they had bought into these narratives and ever experienced The Fear in the first place.

Viewing mental health as linked to things that had happened and were occurring in their lives, allowed participants to move away from seeing it as dependent on biological or

genetic factors outside of their control. Accessing psychological therapy was one process
which facilitated this understanding.

> Understanding myself better and that relationship, how that experience with my
> mum and my upbringing…has made me a lot more…I feel a lot more in control of
> my…wellbeing.... Which makes it feel less likely that you're going to completely
> lose your…cool, at some age. (Niamh)

This tailing off towards the end of the phrase, using 'cool' instead of a word such as
'mind', was something participants did a number of times during the interviews. One
interpretation of this might be that speaking it out loud might have made it feel more
concrete or real.

For other participants, working in mental health roles with people who had
experienced trauma and adversity allowed them to adopt a more psychosocial
understanding of distress. Engaging with critical psychiatry literature (Sarah cited Bentall,
2009) brought Sarah to wholeheartedly disregard the biomedical model, a view which
allowed her to escape The Fear once and for all. Overall, the process of developing
alternative views of psychological distress which moved beyond The Fear took
considerable time and reflection. This supports Johnstone and Boyle's (2018) argument
that biogenetic accounts hinder people from seeing the social causes of distress.

A contrast within this theme came from Alex, whose experiences of The Fear
dissipated once he began to experience mental health difficulties himself, in the form of
depression. For Alex, he appeared to have come to a point of acceptance, that despite his
best efforts, he had not been able to avoid his fate. "I thought I'd escaped it, but no". This

acceptance meant that Alex no longer had to focus his energy on overcoming The Fear, but could instead focus on his own emotional wellbeing.

Theme 2: Signs of (In)sanity - Navigating My Own Mental Health

This super-ordinate theme demonstrates how participants viewed themselves in relation to ideas about their sanity and normality; a relationship that was evolving and dynamic.

Sub-theme 2.1: 'Keeping an eye on things' - Monitoring emotions and behaviour. All participants described a practice of either self-monitoring or self-reflection in order to determine whether they were 'becoming like' their biological parent. The focus of this monitoring/reflection varied between participants. For some, emotions were most closely linked with 'mental illness' and there appeared to be a "hyper-awareness" (Niamh) of their own emotional world. This seemed to have both helpful and unhelpful aspects. It helped participants to feel like they could 'spot' their 'mental illness' early. However, the constant monitoring and worrying about their emotions also added to The Fear and appeared to cause participants to pathologise difficult emotions as 'symptoms' of an emerging 'mental illness'. "I think it has been a blessing and a curse because…has hyper-awareness made you more likely to recognise things? Has it made you more likely to…diagnose things as being unnormal?" (Niamh).

Other participants associated behaviour with 'mental illness' and kept a close eye on how they were acting. As children and young adults, their parents' behaviour was often confusing, concerning, and sometimes scary. Participants also associated acting impulsively, erratically, or 'out of control' with 'mental illness' and would keep an eye on whether their own behaving could be considered in these ways.

'Why am I moving to [a new city], that's so random?' So everything felt like I

wasn't making sensible decisions or I was somehow just making things up as I

went along, and that was in the back of my mind, 'I'm just doing random

things…I'm not in control of my life.' Therefore, it's like a slippery slope to being

like, 'Ah I must be like my mum'. (Niamh)

For Sarah, who never met her biological mother, her focus on behaviour could be viewed

to reflect media and wider societal stereotypes of people diagnosed with 'schizophrenia' as

unpredictable and aggressive or dangerous (Dietrich, Heider, Matschinger, & Angermeyer,

2006; Walker & Read, 2002). While Leigh and Niamh were eager to avoid viewing

themselves as 'insane', Sarah was searching for a psychiatric diagnosis. This served a

function for her as it would have meant that she was not responsible for her behaviour, that

her brain/genes were to blame. This reflects the societal dichotomy between being either

'bad or mad', and perhaps it is better to be mad as this at least means your behaviour is not

your fault (Johnstone, 2000).

Sub-theme 2.2: Participants' relationship to normality. Another aspect of

participants' journey to make sense of their mental health involved a complex and ever

changing relationship to normality. Participants frequently reflected on what they

considered to be normal, what society considered to be normal, and how they and their

family might fit into ideas about normality. There was a constant movement towards and

away from normality as a strategy to navigate these issues and make sense of their own and

their family's identity. It was not uncommon for participants to view their childhoods as

both normal and 'not normal' over the course of the interview. "It was as if it was normal

but looking back the way we're talking maybe it wasn't that normal" (Leigh).

Participants sometimes described their upbringings as 'normal to them'. Embracing normality in this way recognised that some of their experiences might not be viewed as 'standard'. For example, Leigh and Niamh visited their mothers in a psychiatric inpatient ward. However, the fact that it felt 'normal' allowed participants to avoid viewing their family as having anything 'wrong' with them or being abnormal. There was also a striving to appear 'normal' and sane, both to themselves and to other people. For Niamh and Leigh, this meant that they should not express their difficulties or emotions to others. Both Niamh and Leigh became skilled at "putting on an act" (Leigh) to make sure they were seen to be coping with life.

At other points in the interviews, participants conceptualised their experiences as explicitly 'not normal'; this appeared to serve as a way to honour the challenges that their childhood involved. Finally, some participants embraced moving completely away from seeing their family as 'normal' to viewing them as extra-normal.

> I think…we're a very strong family, like not all my friends, and I feel for them actually who've had the normal upbringings, aren't close with their families…we're lucky. So maybe it has brought us all in a way going through everything has brought us closer. (Leigh)

In these instances, participants described their families as unique, resilient, and as having coped with immense hardships in a way that few other families could have. Overall, this complex relationship with (ab)normality culminated in a feeling of pride in participants' families and their shared experiences. However, reaching this point was certainly not an easy path and appeared to be an ongoing process for participants.

Sub-theme 2.3: Participants' relationship to seeking professional support.

Alex, Leigh, and Niamh had experience of their parent accessing support from mental

health services, sometimes involuntarily in the context of being on an inpatient ward.

Sarah's biological mother had also been on an inpatient ward but obviously she did not see

her there. These experiences meant that participants developed a mixed relationship to

mental health services and seeking support. On the one hand, accessing support was very

much normalised as it had been something participants had witnessed for their entire lives.

On the other hand, mental health services were strongly associated with their parent's

'mental illness' and participants viewed accessing support as confirmation that they too

were "bonkers" (Alex). Niamh described this complex relationship to services. "Dad was

able to go…'Go see a doctor' and that didn't feel…strange to me...because actually you

talk to a doctor about your mind". She followed this a few sentences later with, "I don't

mind …taking advice, but I'm not taking…tablets or anything, cos that would make me

crazy". Previous research with family members of people with a diagnosis of

'schizophrenia' has described a similar reluctance to access support from mental health

services due to their family member's past experiences (Stålberg et al., 2004).

In order to avoid accessing support for the mental wellbeing, participants ensured

that they became self-sufficient, coping with their difficulties by themselves. "I did go

through a little psychosis thing myself but I didn't get any services involved and…I know

this sounds weird…but I rode it out myself" (Leigh). A contrast within this sub-theme

came from Alex, who experienced a greater acceptance of his mental health compared to

other participants, something which appeared to allow him to become more accepting of

receiving support for his mental health, both from professionals and from his mother.

Theme 3: 'Who Is My Mum?' - Multiple and Evolving Identities, Relationships, and (Re)connection

This super-ordinate theme describes the many different relationships, or lack thereof, participants had with their biological mothers who experienced 'psychosis'. It also charts how participants viewed their biological mothers as people and the multiple identities their biological mothers came to hold over time. This process was conceptualised as evolving through three 'mother identities': as a mum, as her illness, and as a survivor.

Sub-theme 3.1: My mother as a mum. For Alex, Niamh, and Leigh, the (in)ability of their biological mother to hold a parental, or 'mum', role was a highly important part of their experiences. For Alex, there was little question about this. "She's still always been my mum so like, it [her diagnosis] didn't really change too much". In contrast, both Niamh and Leigh recalled their mothers' inability to fulfil the 'mum role', leading to feelings of loss, anger, and blame. "My mum not being my mum, or not being able to be like a mum, cook dinner, do something, take us out, I think that I found that more difficult" (Niamh). This could be viewed in the context of children being socialised to view mothers primarily as 'mums', whereas fathers are offered numerous possible identities beyond caregivers (Johnson, 2005). Moving beyond these feelings of anger and blame was a difficult process for Niamh and Leigh and appeared to require them to accept that they would never have a mum-child relationship with their mother. In doing this, Leigh and Niamh were able to build a better connection with their mothers, one which resembled an adult-to-adult relationship. This sub-theme was less relevant for Sarah, at least based on the discussions during her interview.

Sub-theme 3.2: My mother as her illness. All four participants described their

biological mother's 'mental illness' as forming a part of her identity, sometimes referred to

as an 'illness identity'. This was particularly the case for Sarah, who at one point in her

life did not know much else about her biological mother. She described viewing 'the

illness' as the primary part of her identity. "So I think I just kind of put her in a bit of

a…bracket of…she's a loon" (Sarah). This bracketing off made it easier for Sarah to

distance herself from her biological mother and fits with research linking biogenetic

explanations with an increased desire for social distance (Kvaale, Gottdiener, & Haslam,

2013). Other participants expressed seeing 'the illness' as a permanent part of their

mother, something which they just needed to accept; another example of genetic

essentialism. This process of accepting an 'illness identity' was associated with feelings of

loss for their mother's 'true' identity. Although Alex described his mother's 'illness' as a

substantial part of her identity, he conveyed his desire to hold onto the many other aspects

of her personality and was critical of other family members for failing to see past her

'illness identity'.

Within this 'illness identity', participants also described grappling with ideas about

responsibility and independence, a tension which has been acknowledged in the literature

(Rüsch et al., 2010). Participants appeared to be conflicted between viewing their mothers'

behaviour as something which was in her control, versus something which was the result of

her 'illness'. Holding the former view allowed participants to see their mothers as more

autonomous and created space for hope of change. However, it also meant that

participants could feel frustrated at their mothers for 'being lazy' or acting in ways they

found challenging. "There's been a lot of fights, one of the main fights that is

reoccurring…is my mum doesn't do nothing for herself" (Leigh). At other times, participants emphasised the view that their mother's behaviour was due to her 'illness'. This helped participants by providing them with an explanation for their mothers' behaviour. "Complete…frustration and bewilderment and like, panic…I did not know what was happening to my mum" (Niamh). Equally, it also meant that participants felt the need to suppress or negate their own emotions towards their mother. "You're angry at someone who…can't help the way they are" (Niamh). Viewing a person's behaviour as outside of their control is often reported as a blame-reducing aspect of biogenetic explanations (Haslam & Kvaale, 2015). However, it also appeared to affect participants in less helpful ways. Participants in this study, and in previous research, described feeling responsible and protective of their parent; this will be discussed further in Theme 4.

Sub-theme 3.3: My mother as a survivor. This sub-theme represents the final layer of identity developed by participants relating to how they viewed their mothers – as a survivor. For Leigh, Niamh, and Sarah, developing this survivor identity was the result of a desire and a willingness to learn more about their mothers' personal experiences of psychological distress and the context surrounding this. By reading a candid letter written by her mother about her time as an inpatient, Niamh began to learn more about what her mother had experienced. This led Niamh to develop a more empathic connection to her mother, along with an appreciation and sense of pride in her mother's survival despite her mental health difficulties.

> Just...the sense of survival, I mean I feel incredibly proud now because I've actually realised as an adult that not many survive what my mum went through…and now I look back and seeing that actually she has had psychosis to the point where

she…was considering…killing herself and…then to be such a ball of energy in

life...[I'm] immensely proud. (Niamh)

Leigh echoed this expression of pride for her mother for overcoming adversity and making

it through life. "She is quite a positive character considering" (Leigh). Sarah described a

similar experience of receiving a letter from her biological father which gave her more

information about her biological mother's background and the adversities she had faced.

This psychosocial context expanded her biological mother's identity beyond that of simply

a "loon" (Sarah). Instead, Sarah's description of her biological mother's experiences

brought forwards a tale of survival and endurance. Longden and Read (2017) view

psychosocial explanations, rather than biogenetic accounts, as a means of overcoming

mental health stigma and promoting more compassionate and understanding attitudes

towards mental health difficulties.

Alex's description of his mother as a survivor reflected a tale of ongoing survival.

He cited her ability to offer care and support to other people experiencing mental health

difficulties, even when she was going through struggles of her own, as "astonishing" and

an inspiration. Overall, developing multiple layers to their mothers' identity, especially

those which emphasised survival, appeared to correspond with participants holding a more

understanding and compassionate view of their mothers. This allowed them to lift some of

the blame they might have held previously and was an important step in them reconnecting

to their mothers, either in person or conceptually.

Theme 4: 'A Caregiver for Your Caregiver' - Multiple Family Roles and

Responsibilities

The final super-ordinate theme captures participants' experiences of being placed in

a caregiving role as a result of their parent's mental health difficulties. This theme

illustrates how being in a caregiving role influenced how participants viewed themselves.

As per the previous themes, this appeared to be a process by which participants came to

understand themselves in relation to other people, and to sociocultural narratives about

family roles and responsibilities. Although exploring experiences of caregiving was not

the focus of this study, it did represent a significant aspect of participants' experiences and

thus it is important to include here, even if in less depth. Again, this super-ordinate theme

was less relevant to Sarah, at least based on the discussions during her interview.

    Alex and Niamh described adopting a caregiving role at a young age, something

they were perhaps too young for. Alex spoke about convincing his mother to seek help for

her alcohol misuse. "When you're that old [aged 14]…it's not something you kind of

expect…I mean you think…'Yeah I'm becoming mature', but then it's like, 'Oh shit'".

This quote illustrates the sudden nature of being thrust into a caregiving role which is

perhaps beyond your years, an issue which has been well documented in research with

young caregivers (Aldridge & Becker, 1999). Alex also described having numerous

mental health professionals at his home over the years but not once being asked how he

was coping. This account fits with research which views young people who care for a

parent with a psychiatric diagnosis as under-supported by services and "invisible" to

professionals (Grant, Repper, & Nolan, 2008; Gray, Robinson, & Seddon, 2008, p. 170).

    These care responsibilities were both pragmatic, in terms of making sure the family

home functioned and everyone's basic needs were met, and emotional, as a source of

support for their mother as well as other family members. This multi-supportive role has

been expressed by other children with a mother with a diagnosis of 'schizophrenia'

(Webster, 1992). Holding multiple responsibilities had a significant impact on participants' emotional wellbeing and they received very little guidance or support in doing this, something also acknowledged in the literature (Gray et al., 2008). "It leaves you feeling a bit messed up inside" (Alex); "You feel the responsibilities to make everything OK which can make you quite an anxious person…and can lead to you feeling quite responsible for other people's happiness" (Niamh).

Leigh's experiences at a young age differed as her father attempted to shield and distance her from the stress that was occurring in the family. Even though this may have been helpful at the time, it left Leigh feeling like an unwanted member of the family. "I felt a bit, not pushed…as if I was an outsider. But obviously…you don't want your child to see what's going on". Over time, Leigh also adopted a more caregiving role within the family, one closer to being a parent to her mother. This 'parent role' was also held by Alex and Niamh and appears to be a common phenomenon for other young people with a parent with mental health difficulties (Aldridge, 2006). Although being more involved in the family allowed Leigh to feel more connected and part of the family, she also expressed a sense of loss about not being able to hold a child role in the family.

For these three participants, their caregiving responsibilities were, and continue to be, a substantial challenge in their lives. However, it is a challenge which they have taken on without question. Overall, these participants came to develop an acceptance of the 'non-traditional' roles they have held, and continue to hold, in their family. Moving beyond fixed identity categories of 'child', 'parent', or 'caregiver', and towards more fluid and multi-storied views of themselves appeared to be helpful for participants in navigating their way through their family experiences and lives.

General Discussion

Overall, these four super-ordinate themes chart how participants came to conceptualise their own psychological wellbeing. This conceptualisation was a process that occurred through relationships with: other people, such as their biological parent or with mental health professionals; mental health services, such as seeking (or not seeking) support for their mental health; and with society, such as through societal narratives about the 'causes' of mental health difficulties and ideas about normality. The findings demonstrate how developing an understanding of one's own psychological wellbeing is not an individual or intra-psychic process, but occurs in relation to others and to the systems and society we live in. These ideas reflect a relational view of the self held by social constructionist thinkers (Anderson, 1997; Fishbane, 2001). This views the conceptualisation of the self as a dialogical and fluid process which occurs between people and in a social context. That is, the relational self could be viewed as constantly open to change and influence depending on and in response to the surrounding social environment (Smith, 1999).

In the context of this study, participants did not appear to develop an understanding of their own psychological wellbeing through intra-psychic cognitive processes. Rather, this developed through their relationships with family members, professionals, and engaging with societal narratives; in both a "social and local context" (Anderson, 1997, p. 224). These findings fit with a previous review that explored children's experiences of having a parent diagnosed with a 'mental illness' (Gladstone, Boydell, Seeman, & McKeever, 2011). Gladstone and colleagues suggest that children develop an

understanding of psychological wellbeing through their experiences with their parents, other family members, professionals, and information in the media.

An important over-arching finding across the themes was the process by which participants developed a more psychosocial understanding of themselves and others over time. In doing this, participants situated themselves, their biological parent, and their family in the context of their experiences. This appeared to change how participants developed their psychological wellbeing and identity, something which fits with theoretical accounts of identity put forward by social constructionists (Fishbane, 2001) as well as previous qualitative research exploring identity and the relational self (Smith, 1999). Moving towards a psychosocial understanding of wellbeing appeared to have a significant influence on how participants viewed: their own mental health (for example, worrying less or feeling more in control); their future (as less pre-determined and more hopeful); their biological parent (as a survivor and more than 'just a mum'); their experience within the family (moving from feelings of frustration and blame, towards pride). Indeed, developing a more psychosocial understanding, something which involves viewing people in relation to their social context, has been argued as fostering empathy between people, and moving away from feelings of blame and anger (Jordan, 1997; Longden & Read, 2017).

These changes could all be viewed as moving from a position of certainty, 'fixedness', and categorisation, towards a position which is more fluid, multi-layered, and complex. In other words, participants appeared to initially hold 'either/or' positions – 'I'm either sane or mad'; 'my mother is either my mum, or she isn't'; 'I'm either a child or a caregiver'. Narrative therapy would view these multi-layered and contradictory accounts as making space for developing new and multiple stories about people's lives, rather than

focusing on a specific account (Morgan, 2000). These findings also mirror Mason's

concept of 'safe uncertainty', which aims to move away from a need to 'know' and move

towards a place where people can entertain multiple possibilities (Mason, 2015). In this

study, it appeared that this was indeed the case, with participants often developing new,

more positive, accounts of their parent as they began to move away from more 'certain'

positions.

Across the findings, the process of moving towards a more psychosocial

understanding allowed participants to hold more complex, and often paradoxical,

'both/and' positions – 'My family is both normal and not normal'; 'I'm a caregiver, and a

care-receiver'. This latter position made space for participants to view themselves and

their family in a way that fit with their own unique, subjective experiences rather than

fitting with societal norms or assumptions. In an article focusing on young people with

parents with mental health difficulties, Gladstone, Boydell, and McKeever (2006) argue

that it is important to move away from such binary positions of 'caregiver' and 'care

receiver'.   Instead, these authors view moving towards notions of interdependence as a

means of promoting agency and positive self-conceptualisation.

It is possible that participants moved towards this more 'complex' position,

whether consciously or unconsciously, because it moved them towards an account of their

lives which they wanted, something described in postmodern therapies as a 'preferred

future' (Lethem, 2002). For example, feeling more in control of their own psychological

wellbeing was spoken about positively compared to not being in control.

Methodological Issues and Research Implications

One major issue within this study related to the sample of participants who were recruited. Firstly, the number of participants was towards the lower end of the recommended sample size range for IPA studies (Robinson, 2014). While a smaller sample can limit researchers from making theoretical generalisations, it does allow researchers to perform a deeper analysis of each individual participant. As a strength of this paper, the smaller sample size meant that I could conduct a 'deeper' analysis of each interview and look for similarities and differences between participants (Smith, Flowers, & Larkin, 2009). This allowed me to explore the nuances and complexities within the data, such as the multiple and evolving ways in which participants viewed their biological parent. However, it is always possible that interviewing additional participants would have provided new information or raised important issues not present in this paper. A larger sample might have made it more likely that the themes reflected the experiences of other people with a biological parent with experiences of 'psychosis/schizophrenia'. It is important to acknowledge that the themes will not be representative of everyone's experiences. However, Brocki and Wearden (2006) argue that qualitative research need not strive for data 'saturation', but rather that the analysis is coherent, 'tells a story', and is able to explore the intricacies of the data.

In terms of theoretical generalisability, there was consistency in participants' experiences of The Fear and these findings fit with previous qualitative studies of people with family members who have experienced mental health difficulties. This study is the first known research to explore this notion and its impact on individuals in depth. It is a strength of this study that it has been able to highlight these issues and provide a voice, not

only for the four participants involved but for any individuals with similar family

experiences, which is more likely to be heard within academic and professional circles. In

this way, it is hoped that this paper provides important insights into the experiences of

other people with a biological parent with experience of 'psychosis/schizophrenia'.

In terms of recruitment, I focused my attention on recruitment via social media as

this appeared to allow me to reach the most people. All four participants were recruited

through social media. However, this number was less than my target of six to eight

participants. It is possible that the participants that I was looking for were not members the

particular 'groups' I was targeting. For example, mental health carer organisations or

Facebook support groups for people with family members experiencing mental health

difficulties. I also attended mental health carer support groups in person, however these

were primarily attended by people who had children with mental health difficulties. In

hindsight, it might have been more fruitful to make stronger links with mental health

charities and organisations and spend time talking with staff members who might have

been able to help with recruitment.

In an attempt to maximise recruitment, the inclusion criteria for the study were

broad in terms of age, geographical location, and personal experiences of mental health.

Considering this, it was a strength of this study that the sample was relatively homogenous

across a number of areas. All participants grew up within the UK, were from a similar

generation (aged between 24-33), and had a mother who had experienced ''psychosis' or

received a diagnosis of 'schizophrenia'.   However, one issue with homogeneity was the

fact that Sarah had never met her biological mother and was adopted shortly after birth.

This meant that her upbringing differed to other participants in terms of her interpersonal

experience of having a biological parent with experiences of 'psychosis/schizophrenia/'.
This meant that some themes relevant for other participants, such as the theme relating to
caregiving, were not present in Sarah's interview. Additionally, some questions in the
interview schedule did not yield significant discussion in Sarah's interview, such as a
question about how mental health was discussed in participants' families. It is possible
that there were topics and experiences which I did not ask about which might have
contributed a different understanding to the analysis. With hindsight, I would have made
an inclusion criterion that participants needed to have grown up with their biological
parent. This would have increased the homogeneity of the sample further. However, given
that inclusion criteria had been specified and I had recruited a small sample, another option
might have been to purposively recruit additional participants who had been adopted away
from their biological parent, as Sarah had. Including only one participant who had not met
their biological parent limits the degree to which the findings can be generalised to other
people who have been adopted (Robinson, 2014; Smith & Osborn, 2004). Including Sarah
in the findings also impacted the confidence to which the findings can be generalised to
people who grew up with their biological parents. As such, any generalisations of the
concepts and implications proposed by this study should be made cautiously.

Importantly, the focus of this study and the research question were relevant and
meaningful for Sarah, as well as for the other participants (Smith et al., 2009). Even
though Sarah had not had a face-to-face relationship with her biological mother, the
process by which she came to conceptualise psychological wellbeing mirrored the
relational process and movement towards both/and positions experienced by the other three
participants.

As all participants had a biological mother with experiences of 'psychosis/schizophrenia', it is unclear what aspects of the findings would be relevant for people with a father with a psychiatric diagnosis. It is possible that these experiences might be different given the societal gender roles of mothers and fathers in child-raising, as well as historical views of women as 'responsible' for their child's mental health difficulties (Worell, 2003). It is likely that the findings of this study, particularly relating to The Fear, are relevant to people who have other relatives, such as siblings or grandparents, with experiences of 'psychosis' or a diagnosis of 'schizophrenia'. However, this should be explored further. Similarly, it is probable that the findings are relevant for people with a biological parent with another psychiatric diagnosis associated with strong biogenetic accounts, such as 'bipolar disorder', 'depression', or 'borderline personality disorder'. Again however, these claims are speculative and warrant future research.

A key finding across the four super-ordinate themes related to how participants developed a more psychosocial understanding of wellbeing and identity, and how this allowed them to view themselves and their families in different and often more helpful ways. A clinically relevant topic of future research would be to explore how therapists and mental health professionals engage in discussions with individuals who have a family member with experiences of 'psychosis/schizophrenia', and more specifically, how these conversations facilitate this process of moving towards psychosocial understandings and 'both/and' positions.

Practical Implications

This study raises a number of important implications for mental health professionals working with people who have a parent who has experienced 'psychosis' or

received a diagnosis of 'schizophrenia'. Overall, the findings highlight the importance of deconstructing societal narratives relating to mental health and wellbeing, normality, and family roles. Clinicians could draw on ideas from systemic therapy which aim to address these issues, as well helping people to live with ambiguity, uncertainty, contradiction (Boston, 2000). The findings provide insight into the many ways having a biological parent with experiences of 'psychosis/schizophrenia' might impact on an individual. It is therefore important that professionals explore not only individual experiences of psychological distress, but also relational experiences between an individual and their biological parent, as well as their relationships and role within the family as a whole.

All participants expressed difficulties and distress associated with adopting a caregiving roll within the family. Professionals should be conscious of this when working with individuals and families and ensure that both emotional and practical support is offered to young carers. Offering a space for young people to express and normalise their experiences of caregiving is also recommended. Professionals should inform individuals and families about the presence of carer support organisations specifically for young people, if these are available in their area.

The common experience of The Fear among participants, primarily during adolescence and early adulthood, suggests that professionals should actively name and offer to explore these issues, even if the individual has not expressed these. This does raise an ethical issue of possibly giving young people ideas about 'hereditary mental illness', something which was navigated in this study by remaining close to participants' words and explanations of mental health. However, I would argue that, in the UK at least, these narratives are almost impossible to avoid and young people will be very much aware of

them already. Normalising these experiences of The Fear should also be an important part of these discussions. Professionals should also consider exploring other issues raised in the findings, such as the tendency for participants to pathologise their emotions or to avoid seeking professional support for their mental health.

Professionals may also have an important role in the process of navigating, and eventually escaping or moving beyond, The Fear. Perhaps most importantly, psychoeducational material should be presented in a way which makes space for possibilities and uncertainty, rather than presented as factual. The findings suggest that exploring psychosocial explanations for a person's parent's mental health difficulties, and indeed their own, can help people to move away from deterministic views of mental health, towards a view in which they have greater control over their own wellbeing. In this study, psychosocial explanations also appeared to be important in facilitating more compassionate and understanding relationships between individuals and their biological parents and other family members.

Psychological formulation may provide one possible means of emphasising the psychosocial factors relating to a family member's mental health difficulties. Niamh explicitly mentioned finding attachment theory to be a helpful framework for her in making sense of her upbringing. Psychosocial accounts also appeared to allow participants to develop a more understanding and compassionate view of their parent, one which emphasised personal strengths and survival abilities. Clinical psychologists, for whom psychological formulation is a core professional skill (British Psychological Society, 2011), may have a particular role in developing a psychosocial understanding based on life experience, social context, and psychological theories.

Conclusion

This study explored the experiences of individuals with a biological parent with experiences of 'psychosis' or a diagnosis of 'schizophrenia'. It provided insight into the complex processes by which individuals make sense of and conceptualise psychological wellbeing and identity. Specifically, the findings showed how participants drew on biogenetic and psychosocial accounts of mental health difficulties, and how these accounts influenced and impacted on their own psychological wellbeing. The findings also contributed to research looking at how a parent's experiences of 'psychosis' or 'schizophrenia' can affect a child's relationship to their parent and the child's role within the family. It is hoped that the issues highlighted in this study can be put into practice by mental health professionals in a way that is helpful for individuals and families.

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Table 1.

Participant Information and Information About their Biological Parent who had Experiences of Psychosis or a Diagnosis of

Schizophrenia.

Participant (pseudonym)	Age	Gender	Ethnicity	Other important cultural identities	Biological parent with a psychiatric diagnosis and their age	Biological parent's psychiatric diagnosis or mental health experiences
Leigh	33	Female	White-Caucasian	-	Mother, 60	Bipolar and schizophrenia
Niamh	26	Female	White-British	Irish, working class background	Mother, 60	Bipolar, experiences of psychosis
Sarah	27	Female	Mixed – White/Black African	Middle class, agnostic	Mother, 63	Paranoid schizophrenia
Alex	24	Male	White-British	Economically working class	Mother, 58	Paranoid schizophrenia

Note. Sarah was adopted as an infant and had never met her biological mother.

Table 2.

Table of Super-Ordinate Themes and Sub-Themes from Analysis.

	Theme 1	Theme 2	Theme 3	Theme 4
Super-ordinate Themes	The Fear	Signs of (In)sanity - Navigating My Own Mental Health	'Who Is My Mum?' - Multiple and Evolving Identities, Relationships, and (Re)connection	'A Caregiver for Your Caregiver' - Multiple Family Roles and Responsibilities
Sub-theme 1	1.1: Knowing 'The Fear'	2.1 'Keeping an eye on things' - Monitoring emotions and behaviour	3.1: My mother as a mum	-
Sub-theme 2	1.2: Uncertainty about the certain	2.2 Participants' relationship to normality	3.2: My mother as her illness	-
Sub-theme 3	1.3: Escaping 'The Fear'	2.3: Participants' relationship to seeking professional support	3.3: My mother as a survivor	-

Appendix 2-A

Journal of Psychosocial Rehabilitation author guidelines

Please see the journal guidelines in Appendix 1-E.

Appendix 2-B

Transcript Examples and Theme Development

Transcript	Initial notes	Initial themes	Super-ordinate theme and sub-themes
Niamh: Particularly when cos she's got bipolar, when she's in the depressive elements of bipolar um…she like couldn't, like didn't want to make breakfast or didn't want to make tea, there's a lot of sadness and anger about that…but when you're being told that mum's not very well, so we all have to look after her, you can't let that anger and sadness out, so you just end up like…internalizing it and I imagine that's not very healthy…	Linguistic comment – "didn't want" – a choice, she was lazy – agency. Blame mum for choosing not to fulfil mum role – but also sympathy that she wasn't able to. Nobody to communicate emotions to. It would be harmful to mum to express these emotions. My own emotions can be bad for other people.	View of mother being responsible for and in control of her behaviour. My mum is not 'my mum'. Mum's illness identity. Emotions can make people crazy.	Mum's multiple and evolving identities Navigating my own sanity
Leigh: The fear of…just the fear of 'it's going to happen to me', and then later in life I did go through a little psychosis thing myself but I didn't get any services involved and I did…I know this sounds weird, but I rode it out myself.	The fear of hereditary mental illness – "going to happen" – inevitable. My choice not to get services involved. Knows what psychiatric hospital looks like from visiting mum – wants to avoid. "Weird" – awareness that most people would have sought help.	Certainty about inheriting mental illness. Being in control of my own mental health – coping important in staying sane. Services would have confirmed that I was mentally ill.	Uncertainty about the certain The Fear - Signs of (in)sanity

Sarah: I think it [seeking a psychiatric diagnosis] was my way of like, not trying to take responsibility for some of the things, ways I was being or behaving.	Seeking a diagnosis to avoid responsibility Societal narrative that people with 'mental illness' aren't responsible for their behaviour.	Brain is to blame Better to be mad than bad	Signs of (in)sanity
Alex: Yeah it's like taking on the duty of the caregiver, for somebody who's your caregiver Me: And how was that for you doing that? Alex: Um….it was quite difficult. It's got easier over time. You know I was a young lad, who was just like…don't know, it's…it's…especially, um…cos my mum is obviously my only parent, so um…like…having to help her through moments of extreme weakness, it was quite difficult. You know…it leaves you feeling a bit messed up inside.	Dual roles in the home – as caring and cared for How did he navigate this? Mum's vulnerability – fragile Had to learn to provide caregiving role himself, no other parent to model himself on How did it mess him up?	A caregiver to your caregiver Mum as her illness Burden of providing care Nobody to support him	Mum's multiple and evolving identities Navigating my own sanity

Appendix 2-C

Table Demonstrating Analysis and Development of Emerging Themes for Each

Participant

Participant	Main theme	Sub-themes
Leigh	Uncertainty about the certain	Knowing the fear
		Escaping the fear
		Explanatory models of mental health
	Signs of sanity: What's normal and what's mad	My own coping and mental health
		Sane/insane identity
		Relationship with normality
	The family journey	Shifting roles in the family
		Family identity
		My own role in the family
		Illness in the home and protection
	Parent theme	View of my mum
		Relationship with mum
Niamh	Navigating my own sanity	Keeping an eye on things
		The fear – Possibilities
		Being viewed as crazy by myself and others
		Taking charge – Control and certainty
		Views of mental health
		Communication about mental health means I'm crazy
	Putting the pieces together	Lifting the blame – Acknowledging the impact of childhood, free from judgement
		Assessing normality
		Views on mental health – Making links to childhood
	Juggling act – Multiple roles in the family	Emotional sponge – Soaking up danger
		Pragmatic carer
		Protector
	Mum theme – Evolving identity and relationship	Just want A relationship
		My mum is not my mum
		Mum as her illness

Participant	Main theme	Sub-themes
Sarah	It's part of me – Viewing my own mental health now and in the future	What if this is the beginning? – Destined path
		Searching for an answer – Better to be mad than bad
		Acting crazy – Schizophrenia is behavioural rather than emotional
	Dropping the medical model	Overcoming the fear
		Becoming critical of the medical model – Moving towards psychosocial understandings
	My mum - Getting to know the person	Mum as a loon
		Mum as a person
	Family narrative about mental health	Communication about mental health in the family
Alex	Accepting your destiny - A rich tapestry	Views of own mental health
		The family ghost
		View of normality
	Mum's identities	Mum will always be my mum
		Mum as an other – Different to me
		Illness identity
	Caregiving theme	Too young to be a carer
		A caregiver to your caregiver
		Equal caring relationship

Appendix 2-D

Narrative Description of Emerging Themes for Each Participant

These narrative theme descriptions were used to develop my ideas about emerging themes from each participant. The descriptions were discussed in supervision to aid the development of the final findings.

<u>**Leigh**</u>

<u>Knowing the fear - Uncertainty about the certain</u>

This theme represents Leigh's journey from her initial confrontation with 'the fear' of hereditary mental illness, through to creating possibilities for a future other than one in which she is mentally ill. It follows her from her position of "knowing the fear" – that she would definitely, at some point, become like her mother. Even though there is a sense that Leigh is certain about her 'prognosis', there is an element of uncertainty regarding when or how she might become mentally ill. At first, this uncertainty creates a downward spiral of fear, panic, and a sense of impending doom. Leigh feels that she has been robbed of possibilities for a different future. With time, Leigh begins to view her uncertain future as one with two possible outcomes, one in which she become ill, and one in which she does not. Although this shifts her certainty about the future, the fear remains. However, the shift towards possibilities begins Leigh's journey towards 'escaping the fear' – to a position where she no longer worries about becoming unwell. Leigh begins searching for alternative explanations and answers. She draws on the experiences of her family for evidence that not everyone in her family inherits mental illness, and seeks reassurance from family members. Learning about statistics about familial mental health also creates probabilities/possibilities for her, that there is more uncertainty to her 'certain future' than she once thought. Eventually she describes the genetic narrative as mythical and looks to disprove it. Leigh also experiences shame about believing in it in the first place.

<u>Signs of sanity</u>

This theme is about Leigh's ongoing process of understanding what madness is, and assessing how this might relate to her. It includes a complex relationship with (ab)normality – it is important for her to define what normal is and is not, and how her and her family might relate to ideas about normality and abnormality. At times Leigh redefines normality to include her own experiences, at other times she conceptualises her experiences as abnormal or extranormal. Both of these views appear to serve different functions and help Leigh to: avoid considering everyone in her family, including herself, as mad; focus on her family's ability to cope with adversity, acknowledge the difficulties her family went through, and to view her family as unique and extraordinary. This represents a constant moving towards and away from normality as a way to navigate the 'realities' of what has happened to Leigh's family and the way she views herself and her family in relation to these events and experiences. Both in the interview, and perhaps in her life, this

complex relationship with (ab)normality culminates in a feeling of pride, however reaching this point was certainly not an easy path and is an ongoing process.

This theme also relates to searching for Leigh's own signs of (in)sanity. This took various forms which were often strategies to ensure that she wasn't going crazy, such as: monitoring her emotions and behaviour for indications that she could be going mad; keeping her difficulties to herself so other didn't view her as mad; become self-sufficient so she didn't need support; making sure that she was coping and that she was seen to be coping;

The family journey

This theme relates to the Leigh's family's shifting/evolving identity and each family member's evolving role within the family. In terms of the family's identity as a whole, this initially focused on mental health as an organising principle for the family. Multiple family members had received a psychiatric diagnosis and there appeared to be a 'family fear'/'time bomb' which was not talked about and which should not be talked about in case it made it true. Being a service user was spoken about as if it was a family profession, one which was 'in their blood'. This contrasted with later accounts of the family mental health story as bringing the family closer together, fostering resilience, and making them stronger as a unit. Leigh expressed a sense of pride in how the family had managed to not only make it through this journey, but how they had grown as a result. The family journey also entailed each family member adopting different roles and positions, often ones they were not prepared for. When her mum went into hospital, Leigh was initially protected by her father and family in an attempt to shield her from what was going on. This left Leigh feeling like an outsider and unwanted member of the family. Over time, Leigh adopted a more caring/responsible role within the family – one closer to being a parent. Although being more involved in the family allowed Leigh to feel more connected and part of the family – she also expressed a sense of grief/loss about not being able to hold a child role in the family. The roles each family member adopted often sounded closer to work, with each family member doing what needed to be done to keep the family together.

Who is my mum? – Changing identities and relationships

This theme charts Leigh's journey to understand who her mother is through her changing relationship with her. This theme begins with Leigh as a child, longing for a reciprocal relationship with her mother, but also wanting to have *any* sort of relationship. However, even this was difficult due her mother being physically and emotionally absent. With her mother not able to adopt a maternal role in her life, Leigh appears to experience an internal conflict between wanting to see the best in her mother and blaming her for not being able to 'be a mum' to Leigh. As Leigh grew up, she went through a process of loss over realising that her mother was not able to 'be a mum' to her and that she had to accept a different identity – one based on illness. This experience of losing her 'mum' was described as worse than her mother being absent. Over time, Leigh was able to accept this new identity and begin the process of building a new relationship with her mother. Leigh acknowledged that this relationship had its limitations, barriers, and frustrations – however,

as when she was a child, Leigh is just happy to have a relationship of some kind with her mother. This new relationship has corresponded with Leigh lifting the blame she previously had of her mother and she has begun to add a new layer to her mother's identity – one of a survivor.

Niamh

This theme focuses on how Niamh views her own sanity and charts how she makes the journey from fearing madness and questioning her sanity to taking control of her mental wellbeing.

The fear inside/outside

This theme documents Niamh's fear of inheriting her mum's mental illness – describing this as both a potential which lurks inside her which is part of her identity, and as something which both follows her and is waiting for her, a sort of spectre. This inside/outside location of mental illness acts as an uncertainty/certainty dialectic – it is a *possibility* which is *definitely* in her body/genes/biology; it is following her looking for a *chance* to strike but is also waiting for her when she *inevitably* reaches it. In order to escape from this inside/outside fear, Niamh makes space for hope by latching onto possibilities of not being insane by seeking reassurance from family members, looking at 'local evidence' in her family that not everyone inherits mental illness, making psychosocial hypotheses/explanations about her own mental health; and questioning biogenetic evidence. During the interview it is clear that Niamh continues to draw on a combination of genetic and psychosocial explanations, sometimes flipping between the two, at other times falling somewhere in the middle (holding a stress-vulnerability model). Even though Niamh has created possibilities for herself which do not entail her 'going mad', she continues to entertain the possibility that there is a 'switch which just hasn't been flicked yet'.

Navigating my own sanity

This theme charts how Niamh makes the journey from questioning her sanity to taking control of her mental wellbeing.   Along this journey, Niamh appears to be constantly aware of and monitoring her sanity/wellbeing and how it is viewed by herself and by other people. She experiences a hyper-awareness of her emotions, behaviour, and ability to cope, in order to 'keep an eye on things'. This is both a blessing and a curse for Niamh in that it helps her to feel like she can 'catch' her mental illness early, but that the constant monitoring also adds to her fear of madness and she pathologises any emotions she experiences. She also learned that expressing your emotions could have an impact on other people and she would keep her feelings to herself so as not to upset her mum. Niamh is also very aware of appearing 'normal' – by not expressing her difficulties or emotions to others, and that she is seen to coping just fine with everything. These are all things she associates with madness.

Niamh also has a mixed relationship with seeking professional support. On one hand, having contact with mental health professionals feels like 'normal' because her mum has done this often, but at the same time it is a sign that you are not 'normal' because you need help.

Because of her early experiences, Niamh has associated being in control with being sane/OK. As such, this was a strategy she used as a child to help her to feel 'normal'. However, once Niamh left home she discovered that the world is not as easy to control as the home environment, this led to a period of distress and a crisis of identity – which heightened her fear of insanity. Over time, Niamh overcame this by shifting her emphasis on control to one of agency – from the outside world to the inside world. Developing a sense of agency about how she responded to events in the world which were beyond her control allowed her to view her mental wellbeing as something which she was more or less in charge of – this alleviated the fear and challenged deterministic views of her sanity.

Putting the pieces together

This theme is about Niamh looking back at her childhood and the process by which she makes sense of her experiences and how they have impacted her. Developing an understanding of her childhood which linked her past experiences to her current emotional wellbeing has allowed Niamh to lift some of the blame and judgement she had about her mum. Niamh draws on attachment-based explanations in order to do this. There is also a relationship to normality in relation to her childhood. At times, she views her childhood as normal and she cherishes these aspects of it. Holding onto normality appeared to function as a way for her to cope with things, so that she could focus on just 'getting through'. However, at other times she acknowledges that it was anything but normal and that it had a big impact on her and her family. This relationship with normality eventually leads Niamh to express a sense of pride about her family and ability to survive – 'normal people couldn't handle our family'.

Juggling act

This theme illustrates the multiple roles Niamh has had to hold within her family in order to keep home life functioning. There appeared to be three main roles described. One as a sort of 'emotional sponge' to soak up emotions/upset which could be a danger to her mum's emotional wellbeing and lead her to have a relapse. This was a 'high stakes' role as getting it wrong would mean that her mum would become unwell and absent again. This role meant that Niamh became responsible for other people's wellbeing, in addition to her own. All the emotions in the family, including both her mum's and her dad's, were soaked up by Niamh, and she had nobody to talk about these with (as talked about in previous theme). This did mean that Niamh has become very perceptive of other people's emotions, a strength of hers. Niamh also adopted the role of *pragmatic carer* – keeping stability and organisation in the household. In Niamh's perceptions as a child, she learned that her family has two possible positions – being OK and being in crisis. It became her job to ensure that things stayed in OK. Niamh modelled this role on her dad, who also held a pragmatic carer role – and she viewed him as a hero – Niamh was also proud of her role in the family. This role cause Niamh to have a focus on practical rather than emotional

caregiving. Finally, Niamh held a protective role in the family, for all family members.
She would also be responsible for protecting the family from some of her mum's
behaviour. Overall, these multiple roles meant that Niamh was under a huge amount of
stress and was not able to acknowledge her own wellbeing.

Mum theme – Multiple and evolving identities, relationships, and (re)connection.

        This theme follows Niamh's changing relationship with her mother and how this
has related to how she has viewed her mother's identities. Niamh has always just wanted
to have any sort of relationship with her mother, and would bottle up her own emotions,
suppress feelings of blame, and 'wash over' difficulties just to keep her mother around. At
times Niamh had to choose between having a relationship with her mother and keeping the
home together. Even though Niamh was happy to have any type of relationship, this
relationship did not appear to be a parent-child one, something which both Niamh and her
mother feel they missed out on. Attempting to go back and experience this parent-child
relationship caused Niamh and her mother a lot of effort/distress, and it took time to accept
that this relationship was gone. Moving out of home and getting some distance allowed
Niamh to develop a new adult-adult relationship with her mother and enjoy the positive
qualities of her mother and appreciation that her mother survived her experiences of mental
illness (something Niamh knows many people do not).
        An important part of this theme was the idea that Niamh's mother wasn't her
'mum' – that she wasn't able to fulfil a maternal role. For children, society doesn't offer
any other ways of seeing your mother's identity other than that of a mum. As a result,
Niamh didn't have any other positive ways to view her mother and she was forced to focus
on how she had 'failed' in her mum role.   At the same time, Niamh was aware during the
interview of not sounding critical of her mother, that she was still her mum even though
she hadn't fulfilled that role. Because Niamh's mother did not fill the maternal role, there
were times when Niamh had to act as a mum to her brother. Niamh's mother appeared to
feel threatened by this and it led to conflict between them. With time, Niamh began to
learn more about what her mother was experiencing when she was unwell. Developing an
empathic connection with her mother was both new and emotionally challenging as it had
been easier to not do this previously. However, it allowed to Niamh to add layers to her
mother's identity as a person, not just as a 'mum'.
        While Niamh's mother was not able to hold a positive 'mum' identity, she did hold
an identity which centred around her illness. For Niamh, this illness identity appears to be
an enduring one and has remained even during periods when Niamh's mother was doing
well. There is a sense of loss for her mother's true identity held by both Niamh and her
family.   Niamh experiences a sense of conflict about whether her mother's 'unusual' or
challenging behaviours are part of the illness ("something being done to her") or are under
her mother's control. At some points, Niamh views these behaviours as under her
mother's control, leading to feelings of anger and frustration. At other times, Niamh views
her mother's illness as separate from who she is as a person, seeing some of her 'unusual'
behaviours as representative of the illness and not of her mum. Small instances of greater
control and agency demonstrated by Niamh's mother are held onto by Niamh, perhaps as a
sign of her 'real mum' resisting the illness identity. This is exemplified by Niamh's sense
of "weird pride" in her mother's survival despite the illness.

<u>Sarah</u>

<u>It's part of me</u>

Sarah's relationship with 'the fear' of hereditary mental illness is initially subtle, simmering below the surface, something in the back of her mind. When she finds out about her biological mother's diagnosis, she experiences some worry about this but nothing she is overly concerned about. However, during a period of greater anxiety during university, Sarah's worries come to the surface. Knowing about research on the 'at risk' period of 'psychosis' has her questioning whether "this is the beginning". It appears to become her destiny to be insane as it's in her genes and she feels helpless – "a pawn in this genetic game".

Sarah begins to actively seek out a diagnosis for herself on the internet, perhaps as a way to confirm what she already knows. Her behaviour at this time is 'irresponsible' and 'erratic' and finding a diagnosis or a label also served a function for Sarah as it would mean that she wasn't responsible for her behaviour. This reflects the societal dichotomy between either being 'bad or mad' – and perhaps it is better to be mad as it means it's not your fault. This focus on behaviour, rather than emotions, reflects her understanding of 'schizophrenia' (her biological mother's diagnosis) which she gained through a social worker's report and perhaps also absorbed through the media (rather than seeing it first hand like other participants). The social worker's report described Sarah's biological mother as aggressive. This could be combined with narratives about schizophrenia within mainstream media which focus on dangerous or antisocial behaviour. Therefore, Sarah might have been checking to see whether she was 'acting crazy', and less focused on any of the 'emotional symptoms' of her sanity.

<u>Dropping the medical model</u>

This theme reflects Sarah's journey to overcome to fear by eventually completely dropping the medical model. This process began when she saw counsellor during the time when she was worried about becoming insane. The counsellor told her that genetic mental illness was bullshit, something which allowed her to question the fear for the first time. This in itself was not enough but it allowed her to be more receptive to counter evidence over time. As Sarah began to feel more in control of her mental health she began to see herself as her own evidence against genetic mental illness. Sarah encountered anti-psychiatry literature and began applying this way of understanding to her work as a mental health support worker. Seeing first hand in her work that people with psychiatric diagnoses had experienced trauma/adversity provided more evidence that a psychosocial model provided a better understanding than the medical model.

<u>Getting to know the person</u>

This theme looks at Sarah's view of her biological mother, whom she had never met. It follows Sarah from her initial view of her mum as a 'loon', someone to be distanced from both physically and emotionally. This may have served Sarah as a way to

distance her own identity from an illness identity. While there is a societal expectation to have a relationship with one's mother, the fact that Sarah's mother held an illness identity overrode any possible 'mum' identity, making it easier for her to not have contact with her and not feel guilty about this. When Sarah began to learn more about her mum's history and context, this allowed Sarah to see her more as a person. This psychosocial context expanded Sarah's mother's identity beyond merely a 'loon'. Instead, Sarah's description of her biological mother's experiences brought forewords a tale of survival and endurance.

Alex

Accepting your destiny - A rich tapestry – The family ghost

This theme documents the rich tapestry of mental illness in Alex's family, and is relationship to this. The rich tapestry is spoken about as a well established fact, which he has no reason to question. It also represents an ever present family ghost, which haunts Alex through his teenage years. Everyone in Alex's family appears to have an understanding of this rich tapestry and he receives a warning from another family member. Alex describes knowing about the family history of mental illness and that he has been keeping an eye on his mental health since he was 14. Alex draws on his experiences of seeing his brother and mother depressed, suicidal, and psychotic – he knows what to look out for and he is eager to catch it early. Even before he experiences mental health difficulties, Alex views it as something which might happen in his future – a possibility – but something which he has no control over – destiny.

Holding this idea of a family tradition of MH means that once Alex begins experiencing what he and his doctor label depression, he is quick to accept this 'fate'. While he previously associated accessing mental health services with being bonkers, once he accepts that he hasn't escaped family mental illness he is able to access support which he founds very helpful. Although he has a good understanding of mental health difficulties, he still wants to turn to his family for help in understanding what he is going through.

Caregiving theme

Holding a carer/caregiving role represents a key aspect of Alex's upbringing. He describes it as something which he did out of duty and responsibility, something which he more or less just did out of necessity. However, he also acknowledges that it was incredibly difficult and placed a huge strain on him – "it messed me up inside". Alex describes being thrust into this role and having a sudden realisation about just how difficult life could be. As the sole carer within the house, his caregiving roles were multiple – he was responsible for his mum's basic needs, such as food, drink, sleep; he offered emotional and social support during difficult times; and he was also responsible at times for taking charge of his mum's reality, trying to help her tell what was real and what was part of her 'psychosis'. This would sometimes make Alex feel frustrated and annoyed and he didn't appear to have much of an outlet for this, having to bottle it up. However, there is also something fulfilling about Alex's caregiving role. Alex's past mental health difficulties and recent neurological difficulties mean that his mother and him now have a reciprocal

caregiving role and look out for each other.   This more equal caring relationship appears to have alleviated some of the frustrations Alex experienced in the past.

Mum's identities

        This theme looks at Alex's view of his mother and how he develops and pieces together/synthesises her multiple identities. For Alex, his mother is his mum first and foremost, something which won't ever change; he makes clear on a number of occasions. This reflects is awareness that other people in his family, and in society, view her as a mental patient first and foremost. Although Alex has always viewed his mother as a mum first, his view of her has evolved over time to include other layers of identity. Indeed, the illness identity does form part of this. Learning about his mother's diagnosis has been helpful for Alex in that it gave him an explanation for his mother's behaviour which he found difficult to understand growing up – he always knew there was something different about her but couldn't put his finger on it. At the same time, a diagnosis as an explanation also appears to be an incomplete one, and Alex finds some of her behaviour tough to make sense of on occasions. Alex's mother's mental illness represents a fixed and integral part of who she is as a person. It leads him to view her as fundamentally different to himself at times. There are other instances where he views her illness as very separate to her, as an entity which has its own behaviours which are different to his mother's other behaviours. He is proud of her caring nature, even when she is experiencing difficulties/distress, but also views her as vulnerable and fragile. Overall, Alex's view of his mum could be summarised as he views her as a normal but insane person.
        Alex's first-hand experience and awareness of the 'illness identity' at a broader societal level has him viewing it as a social justice issue. Alex's multiple view of his mother allows him to stick up for her when other people write her off as a mental or criticise her for her illness. He actively resists and sticks up for his mother, and for every person with mental health difficulties, in the face of stigma, injustice, and discrimination.

Section Three: Critical Appraisal

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This critical appraisal will discuss: the findings of the empirical paper; my own motivations for conducting this study and my own role within the research; the influence of this research on my own clinical practice; issues surrounding the impact of biogenetic accounts of psychological distress; and the intended impact of the research. Methodological and ethical issues will be discussed throughout.

Summary of Findings

Overall, this thesis has utilised qualitative methodologies to explore individuals' subjective experiences of 'psychosis' and 'schizophrenia' across a number of contexts. The systematic literature review looked at people's experiences of accessing specialist Early Intervention Services (EIS) for 'psychosis'; the empirical paper focused on the experiences of individuals who had a biological parent who had experiences of 'psychosis' or a diagnosis of 'schizophrenia'. An over-arching theme across the two papers was the process by which individuals developed their own understanding of 'psychosis' through relationships with others (family members, mental health professionals, peers with lived experience), mental health services, and society. This relational understanding influenced not only how individuals viewed 'psychosis' as a concept, but more importantly, how they made sense of their own psychological wellbeing, as well as the wellbeing of their family members.

This thesis explored the experiences of four people who had a biological parent with experiences of 'psychosis' or a diagnosis of 'schizophrenia'. The study aimed to explore how these individuals made sense of their own psychological wellbeing and how they drew on biogenetic versus psychosocial explanations of psychological distress in doing this. One finding of this study (super-ordinate theme 1: 'The Fear') was that all

participants experienced worries about 'inheriting' their parent's mental health difficulties. This was initially linked with biogenetic accounts of mental health. However, participants drew on psychosocial explanations of psychological distress to move beyond these hereditary worries. The second theme pertained to how participants drew on these explanations to make sense of their own mental health. The third theme explored participants' relationship to their biological parent and how this evolved over time, this was also influenced by psychosocial understandings. The final theme was developed to incorporate participants' experiences of being a caregiver to their biological parent, and the impact that this had on them.

Inspiration for the Research

This thesis topic was inspired primarily by my own personal experiences, but also my experiences on clinical placements and my engagement with the critical and anti-psychiatry movements. As a teenager, I knew that I had an uncle (whom I had not met) with a diagnosis of 'schizophrenia', but this was something which I did not think too much about. However, during a particularly stressful exam period at university I started to worry about my mental health, and when I saw blood dripping from my wall one night I became increasingly worried. Fortunately, this was my only significant experience of 'seeing things' and my worries eventually disappeared.

Just before starting clinical training I encountered Lucy Johnstone's book *Users and Abusers of Psychiatry* (2000) and I began to immerse myself in critical psychiatry books and articles. Over the course of training, I spoke with people, such as friends and clients on placement, who were experiencing fears about inheriting a family member's 'mental illness'. This obviously resonated with my own experience and I was curious why

I had not seen this issue written about within critical psychiatry literature. My instinct was that this was a common experience for people who have one or more family members with a psychiatric diagnosis, and I felt it needed to be explored; hence this thesis.

My Own Role in the Research

Being personally invested in this project certainly helped to sustain my motivation, however it also brought with it a number of issues and challenges. Throughout the research process, I have found it helpful to consider how my own role in the research both "assist[ed] and hinder[ed]" the interpretative and meaning-making processes along the research journey (Lietz, Langer, & Furman, 2006, p. 447). Firstly, my thesis was essentially a critique of the biomedical model, and specifically of the widespread information about 'mental illness running in families' due to genetic reasons. In this way, I hoped that my findings would demonstrate that these messages have a negative impact on the children of people who have received a psychiatric diagnosis. My own view is that there is no meaningful contribution of genetics towards psychological distress, and I view biogenetic accounts as largely unhelpful. Whilst I acknowledge that there are aspects of biogenetic accounts that people value and do find helpful, such as reducing feelings of blame, I believe that these functions can be served by psychosocial approaches. In conducting and writing this research, I have tried to find a balance between honouring participants' experiences and views, and maintaining my own critical stance. I attempted to write the 'introduction' section of the empirical paper from a highly critical perspective. However, in the findings and discussion I made a conscious attempt to write in a more 'neutral' style and stay closer to the views and experiences of participants. However, my decision to adopt quotation marks around medical terms or psychiatric labels such as

'schizophrenia' was one method for maintaining a critical position throughout the paper. It was important to me that I held onto this critical stance, as I believe that many published articles conform to 'mainstream' biomedical language surrounding mental health. Something which, in my opinion, maintains the status quo.

Qualitative research, and certainly interpretative phenomenological analysis (IPA), emphasises/recognises the role of the researcher in the research, including their biases, assumptions, experiences (Hale, Treharne, & Kitas, 2007). At the same time, qualitative research does not make *a priori* predictions or hypotheses (Smith, Larkin, & Flowers, 2009). However, Malterud (2001) argues that researchers generally hold their own personal hypotheses about what they will find, even if these are not formally 'tested'. From the beginning of the research process I had to be conscious of not allowing my own hopes for the findings to filter into the interviews and analysis. I noticed during all of the interviews that I was both pleased and relieved when participants first mentioned their fears of 'inheriting' their parent's 'mental illness'. On some occasions this did not happen until halfway through the interview and I found myself 'picking out' phrases which I thought might lead participants to discuss these worries. I looked back at the moments in each interview when participants first mentioned The Fear to see whether I was 'pushing' participants towards this. Generally, I did focus on specific words or phrases which I felt might lead to conversations about The Fear. However, I believe that my questions were quite open and conveyed little about my own beliefs. For example, in my conversation with Alex, who had been diagnosed with encephalitis:

> Me: How were you viewing your mental health before you had that neurological
>
> understanding, what were you saying to yourself or how were you thinking about
>
> it?
>
> Alex: I was just like, "Ah yes, I thought I'd escaped it, but no, the family tradition
>
> has come to haunt me too'

On the other hand, it was also helpful that I felt so strongly about this topic as this made me extremely aware of my biases because my stance on the topic was very clear. In one attempt to counter this, I made sure to ask about positive or helpful aspects of biogenetic accounts of family mental health.

As I interviewed my second and third participant, some unexpected conversations emerged. I began to hear about participants' evolving understanding of mental health, which incorporated and moved towards psychosocial understandings of distress, including references to attachment theory and to critical psychiatry literature. I had not considered that participants would find their own ways to escape The Fear, and I believe that learning more about these processes added to the implications of the findings. That is, the findings not only highlighted the negative impact of biogenetic accounts, but they also provided insight into how this impact could be navigated and overcome. It was heartening for me that psychosocial ways of understanding psychological distress had been helpful for participants. This reinforced my own view, and the ongoing movement within clinical psychology as a profession (Johnstone & Boyle, 2018), that psychosocial understandings provide a viable and helpful alternative to biomedical accounts of psychological distress.

I was also aware, during the interviews and certainly as I was writing my empirical paper, that being critical of the biomedical model can be a controversial and taboo position.

Some of the participants found aspects of the medical model helpful in understanding themselves and their parent, or at least had identified strongly with the idea of 'mental illness'. I was careful during the interviews to not 'expose' my position, in case this coloured the interviews, or worse still offended participants. I also began to question why being critical of the medical model felt controversial. This was influenced by an interesting exchange with one participant, 'Sarah', who was very critical of the biomedical model herself. At one point during the interview she stopped mid-sentence and exclaimed: "I'm sorry…I don't actually believe schizophrenia exists". At this point, I had to decide whether to share my similar views but opted to save this until after the interview.

Following this, I wrote in my reflective diary, wondering how this disclosure might have shaped the remainder of the interview with Sarah, and even how sharing my views with all participants may have influenced the data. Although I used self-disclosure of my experiences of family mental health in an attempt to reduce the power dynamic between myself and interviewees (Dickson-Swift, James, Kippen, & Liamputtong, 2007), Abell et al. (2006) argue that some forms of self-disclosure lead to 'category entitlement' on the part of the interviewer (expert) to provide information to the interviewee (subject). In the example of my conversation with Sarah, there might have been a danger that she felt that I knew more about critical psychiatry than she did and would not have felt as comfortable discussing her own views.

In specifically recruiting people who had a *biological* parent with experiences of 'psychosis' or a diagnosis 'schizophrenia' I may have implied that the research was interested in biogenetic accounts of mental health, leading participants to make guesses about my motives behind this. I would also suspect that each participant knew that I had

my own personal understanding and opinion about psychological distress/mental health,

and that by withholding this they may have been left wondering what my views were, and

perhaps if I disagreed with what they were saying, or that they were 'getting it wrong'. In

fact, during my interview with Leigh we had an exchange which exemplified this as she

told me about her understanding of psychological distress:

> Leigh: I think it's nature more than hereditary, I think it's just natural to get certain
>
> emotions and fear and that.
>
> Me: So that's kind of the sense that you make of of that? How you always go up and
>
> down, as just about how humans are?
>
> Leigh: That's life
>
> Me: Yeah, so life.
>
> Leigh: Is it?
>
> Me: I don't know, what do you think? I don't have the answers I'm afraid, but is that
>
> kind of how you feel?
>
> Leigh: I think it's life. Yeah I do.

This excerpt also highlights an issue relating to potential epistemological differences

between myself and participants. From this discussion, I could infer that Leigh's position

was closer to positivism, whereby she held that there is an answer, or truth, to what mental

health difficulties 'actually' are. From her perspective, she was perhaps wondering if I had

this answer. My reply conveyed my own social constructionist position – that she had her

own subjective reality and that this is what I was genuinely interested in. In navigating

these potential differences during other interviews, I tried to learn as much as I could about

each participant's explanatory model of psychological distress, either through inquiry or by

listening out for 'clues'. I tried to remain close to participants' perspectives so as not to introduce my own biases. However, I believe that continuing to hold onto a social constructionist position throughout the interviews made space for participants to consider alternative accounts of mental health and multiple understandings of their experiences.

The point in this research process which made me most aware of potential ideological and epistemological differences between myself and participants was during the writing process. It was important for me personally that my thesis remained critical of the biomedical model. At the same time, I wanted to keep a postmodern stance and not privilege my own views, allowing for multiple understandings to be held by participants (Pillow, 2003), including biomedical accounts. In doing this, I was constantly considering what each participant would make of my opinions and interpretations. I found the experience of waiting to hear back from each participant for 'respondent validation' particularly exposing, and quite anxiety provoking. Only one participant (Sarah) responded to this; she had nothing to add to the findings. I was left wondering whether the other participants simply were too busy or did not feel it important to respond, or whether something I had written had conflicted with their own views/experiences and upset them.

My bias towards critical psychiatry also influenced my meta-ethnography. I had to remain constantly aware of my desire to focus on negative experiences of psychiatric diagnosis, medication, and of services as a whole. Many of the studies in my meta-ethnography included generally positive experiences of Early Intervention Services. However, I believe that holding a critical stance throughout the analysis process allowed me to 'pick out' some of the tensions within the themes, which I hope made for a more interesting paper overall.

Influence on My Own Clinical Practice

      Understanding the experiences of children. Having completed this thesis, I have developed a greater understanding of the many ways having a parent with a psychiatric diagnosis impacts on children. I believe this will influence my future clinical work with people who have parent, or other family member, with experiences of 'psychosis' or other mental health difficulties. Prior to conducting this research, I think I would have focused simply on a person's fears or worries about 'inheriting' a 'mental illness'. However, the findings revealed a great deal more about the complexities and processes that go along with these fears, as explored in the super-ordinate theme 'Signs of (in)sanity'. Having a greater awareness of these processes, I may be more likely to hear and 'pick out' these topics in conversations within therapy, or even actively name and enquire about them. Ideas from narrative therapy may provide a means for me to deconstruct societal ideas about normality, 'madness', and different family and gender roles (White, 2007).

      Challenging biogenetic accounts of distress in therapy. A significant and ongoing issue for me in my clinical work is whether to challenge psychiatric diagnosis and biogenetic accounts of distress in therapy, and if so, how this could be done. D'Arrigo-Patrick and colleagues (D'Arrigo-Patrick, Hoff, Knudson-Martin, & Tuttle, 2017) recently published a paper exploring how therapists addressed social justice issues in therapy by adopting different activist positions. In their findings, therapists appeared to adopt two major strategies, sometimes moving between these over the course of a session. To summarise briefly, therapists sometimes engaged in *activism through countering*, through expressing their own views or 'educating' clients about social justice issues. Other therapists adopted an *activism through collaboration* stance, which involved exploring the

impact of social justice issues in an inquisitive and client-led way. My default position in my own practice would be much more of a collaborative approach. However, it was interesting for me that in the case of Sarah, she was told directly that biogenetic accounts of mental health were "bullshit", something which helped her to move beyond her worries of inheriting her biological mother's 'mental illness'.

This has made me question whether I should adopt more of a countering approach towards the biomedical model in my work. The danger here would be in imposing my own views onto people, something which goes against my values. However, there are perhaps other ways of doing this which might offer alternatives to the biomedical model, as a possibility for clients to consider and decide whether these ways of thinking might be helpful for them. Again, narrative therapy provides ways for therapists to adopt an activist stance in therapy, challenging taken for granted assumptions and deconstructing societal discourses, in a way that is collaborative and avoids colonising clients as much as possible (Monk & Gehart, 2003). The recently published Power Threat Meaning Framework (Johnstone & Boyle, 2018), as well as psychological formulation more generally, also represent ways of emphasising psychosocial understandings of a person's experiences, something which helped participants in this study to move beyond biogenetic accounts of mental health.

The Geneticisation of Distress

The main strength of this thesis was that it explored and expanded on an issue that had been alluded to in previous qualitative research and opinion papers. Namely, that biogenetic accounts of psychological distress can have a negative impact on the children of people who receive psychiatric diagnoses. Phelan (2005) hypothesises that biogenetic

accounts of mental health have the most impact on: i) children and younger relatives; ii) family members who may be in the 'at risk' age period for a particular mental health difficulty; and iii) individuals with a psychiatric diagnosis (or whose partner has a psychiatric diagnosis) who are considering having children themselves. The findings of this thesis supported the first of these assertions, as exemplified by the theme 'The Fear' which was discussed in the empirical paper. The other two points, ii) and iii), made by Phelan (2005) are worth exploring in more detail.

Explicit and implicit 'at risk' labels. Only one participant (Sarah) expressed an awareness of an 'at risk period for psychosis', something which contributed to her worries about her own mental health. I did not ask the other participants if they were aware of the 'at risk period' hypothesis, but I was curious whether they had heard of it and what sense they made of this idea. Previous research interviewing people who had been given a formal 'at risk' label by Early Intervention Services found that this label was experienced as largely helpful to individuals as they were given information and received emotional support form professionals, friends, and family (Welsh & Brown, 2013). However, some participants in Welsh and Brown's study also expressed feelings of stigmatisation surrounding this 'at risk label'.

Corcoran, Malaspina, and Hercher (2005) acknowledge that although information about an 'at risk period for psychosis' is provided to aid awareness and 'early detection', it can also have unintended consequences relating to stigmatisation and impact on an individual's view of their current and future mental health, as demonstrated in the empirical paper's findings. This mirrors the findings of the meta-ethnography in this thesis, in which individuals had largely positive experiences of Early Intervention Services

in terms of relationships, support, and receiving information about 'psychosis'. However, individuals also expressed feelings of stigma associated with accessing a specialist mental health service, as well as other unintended consequences, such as feelings of dependence and coercion.

Participants in the empirical paper appeared to hold an implicit 'at risk' label, given to them by themselves, professionals, or society. This implicit label brought with it a number of difficulties, without many of the positive elements described in Welsh and Brown (2013). Participants were largely left dealing with their fears and worries about their mental health on their own, until they either navigated beyond this fear or sought professional support. In focusing on the experiences of people who do not access specialist 'psychosis' services, this thesis has highlighted some of the issues surrounding biogenetic accounts of mental health - that these extend beyond the people who receive psychiatric diagnoses.

Biogenetic accounts and childbearing. Participants in this thesis did not discuss any issues or concerns about having children themselves in terms of 'passing on' any mental health difficulties. This was not a focus of this research and could be a product of me not asking questions about having children. Previous research has already explored this issue, indicating that concerns about "genetic contamination" (Phelan, 2005, p. 310) are widely held by women who have a psychiatric diagnosis who are considering having children (Lawrence, 2011; Paterson, Parker, Fletcher, & Graham, 2013). Women with a psychiatric diagnosis are also sometimes advised by professionals to not have children due to 'genetic risks' (Viguera, Cohen, Bouffard, Whitfield, & Baldessarini, 2002).

On a separate but related topic, one participant's (Niamh) biological mother had experienced post-partum 'psychosis', causing Niamh to worry about her future mental health if she were to have a baby. Although not included in the findings, this represents a novel area of research which came out of the data. Niamh's concerns about post-partum 'psychosis' appeared to be different to her worries about developing 'psychosis' because it was tied to a specific and predictable event, that is, child birth. I could not find any previous research exploring women's experiences of worrying about post-partum 'psychosis' because of possible 'genetic risks', and this would be an interesting topic to explore in future research.

Impact of the Thesis

I hope that the publication of this research will lead to mental health professionals taking the issue of 'The Fear' more seriously. It is a national guideline in England that Early Intervention Services offer every person who accesses the service a family-based intervention (National Institute for Health and Care Excellence [NICE], 2014). Part of this intervention involves 'information sharing' among family members in terms of each family member's understanding of mental health difficulties (Meriden, 2018). This would provide an ideal context in which to explore some of the issues raised by this thesis.

I also aim to publish the findings in a more accessible format on a blog, so that other people with similar family experiences may read it. As was demonstrated in the findings, providing people with alternatives and possibilities outside of hereditary narratives of mental health can be enough to lift and even escape The Fear.

Final Reflections

Carrying out this research has been an enjoyable, interesting, and rewarding process. Choosing a topic that resonated with me personally, and which I felt passionate about, helped me to sustain my enthusiasm for the thesis over its duration. I am extremely grateful to each person who agreed to be interviewed for this research and I felt privileged to be able to listen to their experiences. I hope that providing a voice to the experiences of the participants will be helpful in some way to other similar individuals, and to mental health professionals who might work with them.

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Section Four: Ethics Proposal

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

Title of Project: Experiences of individuals with a biological parent who has experiences of psychosis or a diagnosis of schizophrenia
Name of applicant/researcher: Max Homberger
ACP ID number (if applicable)*:   **Funding source (if applicable)**
Grant code (if applicable):

*If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

x☐ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM   Trainee Clinical Psychologist
2. Contact information for applicant:
E-mail: m.homberger@lancaster.ac.uk   **Telephone**: 07939156934 (please give a number on which you can be contacted at short notice)
Address: DClinPsy Programme
                    Faculty of Health and Medicine
                    Furness College
                    Lancaster University
                    Bailrigg, Lancaster, LA1 4YW
3. **Names and appointments of all members of the research team (including degree where applicable)**
        Dr Suzanne Hodge
        Lecturer in Health Research

Lancaster University
Dr Graeme Reid
Consultant Clinical Psychologist, North West Boroughs Healthcare NHS Foundation Trust &
Associate Lecturer in Clinical Psychology, Lancaster University

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐   Masters by research ☐   PhD Thesis ☐   PhD Pall. Care ☐

PhD Pub. Health ☐   PhD Org. Health & Well Being ☐   PhD Mental Health ☐   MD ☐

DClinPsy SRP ☐   [if SRP Service Evaluation, please also indicate here: ☐]   DClinPsy Thesis x ☐

4. Project supervisor(s), if different from applicant: Dr Suzanne Hodge & Dr Graeme Reid
5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:
Dr Suzanne Hodge – Lecturer in Health Research, Lancaster University
Dr Graeme Reid – Consultant Clinical Psychologist, North West Boroughs Healthcare NHS Trust

SECTION TWO
Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk
3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'
n o

4c. If yes, where relevant has permission / agreement been secured from the website moderator? n o

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? n o

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.

6a. Is the secondary data you will be using in the public domain? n o

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE
Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Numerous studies have observed periods of significant psychological distress (sometimes labelled as 'mental illness') experienced by members of the same family. Over the past few decades, biological and genetic explanations for why 'mental illness runs in families' have become increasingly prominent. Previous research has looked at how viewing psychological distress as an 'inherited disease' impacts the individuals who are diagnosed with a 'mental illness'. However, there is little research looking at how genetic accounts of 'mental illness', including those which incorporate environmental 'triggers' affect offspring of parents who have been diagnosed, who could believe that they have a genetic 'ticking time bomb'. The present study will focus on experiences sometimes labelled as 'psychosis', interviewing individuals (aged 18+) who have one or both biological parents who have experienced 'psychosis' or received a diagnosis of 'schizophrenia'. The study will aim to explore how these individuals view and make sense of their own psychological wellbeing. Gaining a better understanding of how 'psychosis' and

'schizophrenia' impact on their adult offspring is important for clinical psychologists and mental health professionals working with families in the context of specialist psychosis services.

2. **Anticipated project dates (month and year only**)

Start date: 08/2017   End date: 05/2018

Data Collection and Management
For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Participants will have one or both biological parents who have received a diagnosis of 'schizophrenia' or experienced 'psychosis'. Participants will be aged 18 or over. It is recommended that Interpretative Phenomenological Analysis (IPA) studies include a relatively homogenous sample (Smith, Flowers, & Larkin, 2009). It is hoped that, despite the broad age criteria, participants will represent a fairly homogeneous sample due to them sharing a common characteristic of having a biological parent with experiences of psychosis or schizophrenia.

Participants will not be accessing or have accessed specialist psychosis mental health services. This is also to encourage homogeneity in sample in terms of similar experiences of personal mental health. Participants will not be currently accessing mental health services, so as not to 'interfere' with any psychological intervention being undertaken at the time. Participants will be English speakers who speak at a level that they do not require a translator. This is because of funding restrictions associated with the study. It is recommended that Interpretative Phenomenological Analysis (IPA) studies include a relatively homogenous sample (Smith, Flowers, & Larkin, 2009).

The study will aim to recruit between 6-8 individuals to take part in the interviews. This number of participants is sufficiently small to allow for an in-depth analysis of each participant's experiences, while looking for commonalities and differences among participants (Pietkiewicz & Smith, 2012). This number of participants also meets the practical and time demands of a doctoral thesis. The absolute minimum number of participants which would make the study viable would be one, this would then become a case study. Single person studies using an IPA methodology have been published previously (Eatough & Smith, 2006). Demographic information about participants' age, how they identify themselves culturally (e.g. gender, ethnicity), and the age and gender of their parent who has experiences of 'psychosis' or a diagnosis of 'schizophrenia'.

Participants will be excluded if they do not have a biological link to their parent with a diagnosis of 'schizophrenia', that is, if the participant is adopted. Participants will be excluded from the study if they are not fluent English speakers and would require a translator to conduct an interview. There are no exclusion criteria based on geographical location due to the possibility of Skype/phone interview. Participants will be excluded if they are accessing or have accessed specialist mental health services related to psychosis. Participants will be excluded if they are

currently accessing any sort of mental health services. This is to ensure that taking part in the research does not interfere with any ongoing psychological intervention.

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Smith, J.A., Flowers, P. & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, research, practice. London: Sage.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Participants will be recruited via posters placed in community buildings and areas (such as universities, churches, libraries, etc.), online (shared through social media), and by contacting charities or support groups and asking them to distribute the poster by hand, email, or via social media. Posters will be placed around Greater Manchester and the North West of England where the principal investigator (PI) is based. The PI will make every attempt to conduct face-to-face interviews for participants who live within the UK, this will be decided on a case-by-case basis. However, travel limitations of the PI might mean that interviews are conducted via Skype/phone. International interviews will be conducted via Skype/phone. These might be charities which provide support to family members of people experiencing mental health difficulties, such as Mind or SANE. Therefore, participants may be recruited internationally (as long as they are English language speaking). Having seen the study poster, potential participants will contact the principal investigator, Max Homberger, via his University email account or University-issue mobile phone to express their interest in taking part. All volunteering participants will be included given that they meet inclusion/exclusion criteria (stated in Section 3). Once the maximum number of participants has been interviewed (8), any further people who contact the PI about the study will be informed that no more data is being collected and thanked for expressing their interest nonetheless. Having made contact with the PI to express their potential interest in taking part in the study, participants will be sent an information sheet about the study to read ahead of time, as well as the consent form to read ahead of time. At this time, participants will be asked to make an appropriate date/time to hold the interview, venue (home or community building) and decide on a format (face-to-face, phone, Skype). All calls over Skype are encrypted end-to-end by default. Skype calls will be made through a newly created Skype account, call history will be deleted after

each participant has been interviewed, and the Skype account will be deleted once the interviews are complete.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

The study will adopt a qualitative methodology as it is interested in the personal experiences of individuals. Interpretative phenomenological analysis (IPA) will be adopted as the overall methodology. IPA looks at how people make sense of a particular aspect of their experience (Larkin & Thompson, 2012). This methodology fits the research question, which is interested in how people make sense of their own psychological wellbeing in relation to a particular experience, namely, having a biological parent with a diagnosis of 'schizophrenia'.

The data will be collected through a series of semi-structured interviews (one interview per participant) conducted by the PI. The interviews will be informed by an interview schedule, however the exact questions and topics will vary for each participant depending on what they discuss. Interviews will be transcribed verbatim by the PI, including non-verbal detail such as pauses, laughter, crying etc. These transcripts will be used to conduct the analysis.

The process of analysis using IPA will follow that described by Smith, Flowers, and Larkin (2009). The PI will begin by immersing himself in the data, reading and re-reading the first transcript. The PI will make initial notes as he reads the transcript. These notes will then be used to develop emergent themes through a process of interpretation, looking for links, connections, differences, and tension between these themes (Biggerstaff & Thompson, 2008). Themes will then be 'clustered' to form super-ordinate themes. These super-ordinate themes will be checked to ensure that they fit with the original text. This process will be performed again on subsequent transcripts. Once all transcripts have been analysed independently, the PI will attempt to find patterns across the participants. Supervision will be used to check the PI's interpretation, personal reflexivity, and construction of themes. The super-ordinate themes will then be developed into table of final 'master themes'. Pertinent excerpts from the data will be included within each theme to 'give voice' to participants' experiences. The analysis will be fed back to the participants (if they opted in to this) to check the interpretations and analysis. Any feedback will be placed alongside the analysis and discussed. This process of taking analysis and interpretations back to the participants (prior to finishing the research paper) is recommended as a means of ensuring validity in qualitative research (Yardley, 2000). If participants disagree with the researcher's interpretation, the participant's views will be given primacy as the quotes belong to them.

The overall analysis will attempt to follow recommendations outlined by Yardley (2000) for conducting qualitative research with high validity and quality. Analysis will be taken to participants for feedback and to check for misinterpretation of excerpts. A comprehensive audit trail will be kept throughout the analysis processes.

References:

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. Qualitative research in psychology, 5(3), 214-224.

Smith, J.A., Flowers, P. & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, research, practice. London: Sage.

Yardley, L. (2000). Dilemmas in qualitative health research. Psychology and Health, 15(2), 215-228.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.

Data Security and Location: The contact details of the participants will be stored on Box for only as long as is needed to conduct the interviews. The interview transcriptions will be stored on Box (all members of the research team will have access to the transcripts for analysis and supervision purposes).

Demographic information for the participants will also be stored on Box and will be kept in a separate file to the transcripts. Participants will be given a unique ID to link their transcript and demographic information.

Timescale: The data (scanned versions of consent forms, scanned demographic information questionnaires, and transcripts) will be stored for 10 years on the University server

Data Stewardship: Upon completion of the doctoral thesis, the PI will no longer be involved with Lancaster University and the data will be managed by the doctorate in clinical psychology (DClinPsy) programme. Once the PI has completed the doctorate, access to the data will be held by Dr Suzanne Hodge.

7. Will audio or video recording take place?   ☐ no   x☐ audio   ☐ video
a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

After each interview has been completed, Max Homberger will immediately return home to transfer the audio file from the digital recording device to an encrypted USB stick in order to password protect the file. The audio files will then be uploaded to Box (Lancaster University's secure online cloud system) and the original audio file deleted from both the recording device and from the USB stick. Information on Box is automatically backed-up daily. The research team (Max Homberger, Suzanne Hodge, and Graeme Reid) will all have access to these audio files on Box for purposes of supervision. Once the interviews have been transcribed by Max Homberger and checked, the audio files will be deleted.

The digital recording device will not be encrypted so the audio file will be transferred to a password-protected, encrypted USB stick as soon as possible once the researcher conducting the interview has returned home. The audio file will not be stored on a laptop at any point.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Digital audio files will be deleted from the recording device as soon as they have been downloaded to an encrypted USB stick. Digital audio files will be deleted from the USB stick once they have been uploaded to Box. The digital audio files will be destroyed once the doctoral thesis has been submitted. Hard copies of consent forms will be destroyed once they have been uploaded onto Box.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

The data (transcripts and demographic information) will be stored on PURE for 10 years.

8b. Are there any restrictions on sharing your data?

Due to the small sample size, even after anonymisation there is a small risk that participants can be identified. The data will also not be completely anonymous as the PI will know which interview is linked with which participant even after a pseudonym is given or chosen. Therefore, data will only be shared on request with genuine researchers. Access will be granted on a case by case basis by members of the research team.

9. Consent
a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Consent will be obtained via a written consent form (see Appendices). Potential participants will be sent an information sheet and consent form prior to taking part in the interview so that they have a chance to read these documents properly. The participants will be able to contact Max Homberger or other members of the research team prior to taking part if they have any questions or concerns. If participants choose to contact a member of the research team who is not the PI, that member of the research team will notify the PI as soon as possible. Before conducting the interview or asking potential participants to sign the consent form, Max Homberger will discuss the information sheet and consent form with participants and provide an opportunity to ask any questions. For interviews conducted via telephone/Skype, recorded verbal consent will be taken.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Questions during the interview may be emotive and the participant may become upset or distressed. Questions will not involve asking about participants' trauma histories, however answers including information about participants' biological parent/s may include disclosures of

abuse or trauma in relation to the 'explanation/cause' of their 'mental health difficulties'. If a disclosure of abuse is made, the PI will follow Lancashire Care NHS Foundation Trust (LCFT) safeguarding procedure and policy (the PI is an employee of LCFT). If participants become significantly distressed during the interview, the PI will draw on their own clinical skills in listening, validating, and reassuring the participant. The PI will also ask at regular intervals whether the participant would like a break, of if they would like to terminate the interview. Information about sources of support for the participant will be provided on the information sheet.

Participants can officially withdraw their consent to take part in the research at any time before or during the interview. They will also have a period of 14 days following the interview to withdraw from the study. This is because data collection and analysis will be occurring at the same time, as well as the research study being completed as part of a time-limited doctoral thesis which means extracting participants' quoted text, summaries, or conclusions will be impossible after this time.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

As interviews will be conducted in participants' homes or in a community venue, the PI will follow Lancaster University policy relating to lone working. The interviewer will send a link to the file on Box containing the details (name and address) of the participant being interviewed to a 'buddy' (either a supervisor or if a supervisor is not available this will be another trainee clinical psychologist) and contact them before and after the interview. If the buddy does not hear from the interviewer the buddy will attempt to contact the interviewer by phone. If the buddy fails to contact the interviewer, the buddy will open the file containing the participant's personal details and the relevant authorities will be contacted. The interviews may also take place via Skype, the applicant is aware that there may be security issues related to Skype but every attempt will be made to ensure confidential information relating to the participant (i.e. their Skype username) will be deleted. This will also be the case for interviews conducted via telephone – the applicant will delete the participant's phone number from the phone's call history.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are no known benefits from taking part in the interview or research study. However, it is hoped that the research study will influence how mental health professionals work with individuals and families experiencing psychosis/schizophrenia.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Out-of-pocket expenses will be made for participants who travel to a community building (return travel). These expenses will be discussed with the relevant person on the Lancaster DClinPsy programme on a case-by-case basis. The reason for this is that if the applicant ends up

having difficulties with recruitment, a longer journey may need to be made to interview participants.

Participants will be telephoned/Skyped by the PI so will incur no cost for this.

14. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes
b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.
As direct quotations will be used in the final thesis, complete confidentiality cannot be assured for participants. However, all attempts will be made to keep their personal details (name, age, address, gender) separate from their transcript. Each participant will be given a unique identification number to allow this.

There are limits to participant confidentiality. Namely, if the interviewer is concerned that about the safety of the participant, or if there are concerns that the participant may harm themselves, harm others, or be harmed by others. In these instances, the interviewer will follow Lancashire Care NHS Trust safeguarding policy. The interviewer is familiar with this policy. The participant will be informed, when possible, that the interviewer will be breaking confidentiality.

By default, participants will be assigned a pseudonym for their transcripts, demographic information, and direct quotations in the results. Participants will have the option to choose their own pseudonym. This might allow them to follow their own 'voice' throughout the research. Although having the participant aware of their own pseudonym means that each participant will be able to recognise their direct quotes, the applicant believes that participants would be able to do this anyway given the small sample size; being able to link pseudonyms to their age, education, gender, and gender of parent; and being able to remember what they talked about in the interview. As such, the applicant acknowledges that the data will only be anonymised in the sense that people other than the participant won't know who the direct quotes belong to.

An individual with lived-experience consulting on the project proposed this idea, stating that participants might like to use 'a name that belonged more to them' for their quotes, without compromising the anonymity of themselves or their family members.

If data are shared with people outside of the research group – no identifying information outside of that presented in the research paper (that is – pseudonym and demographic information) will be associated with the transcripts.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

People with lived experience relevant to this particular topic (people who have either experiences of psychosis/schizophrenia themselves, or have a parent/relatives who has experiences of psychosis/schizophrenia) have been consulted on the recruitment process, recruitment materials, and interview schedule. These consultants may also be involved in editing

the final paper and/or in co-writing a version of the results for dissemination online. The data will not be shared with anyone outside of the research team involved in co-writing any future papers.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

Max Homberger and the other two research team members will have access to the data for the purpose of supervision of analysis and results.

The final academic paper will be examined as a doctoral thesis. The results from the study may be submitted for publication in an academic or professional journal. Results may be presented as part of professional teaching/training events or at a conference. The results from the study may also be submitted online on a non-academic, non-peer reviewed website (for example, blogs interested in critical approaches to psychiatry/psychology.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

A main ethical consideration of this study relates to the content of the interviews. Some of the questions may cause participants to become concerned about their own psychological wellbeing. The interviewer will stick as closely as possible to the participant's own language and views of 'schizophrenia/psychosis' in order to avoid introducing a different understanding or their own personal views. The interview schedule has been developed in collaboration with individuals with lived experiences similar to the participants to hopefully ensure that the questions do not increase participant's concerns about their mental health. Following the interview, participants will also have an opportunity to discuss any concerns or issues which came up during the interview with Max Homberger. They will also have an opportunity to have a debriefing discussion after the interview, along with the list of resources and sources of support provided on the information sheet.

The applicant acknowledges the potential security issues relating to the use of Skype and has discussed the measures that will be taken to ensure confidentiality. There do not appear to be any security issues relating to 'hacking' of the Skype call itself due to a high level of end-to-end encryption adopted by Skype. It will most likely be more difficult to contain participants' emotional distress over a Skype or telephone interview. It will also be more difficult to pick up on non-verbal cues to participants' emotional state during the interview. As such, the applicant will check in with participants more frequently to see how they are finding the interview.

The option for participants to select their own pseudonym breaks with tradition in most qualitative research. The applicant believes that very little anonymity is lost compared to other qualitative research where it is relatively easy for participants to identify pseudonyms by linking this to demographic information and remembering what they discussed in the interview. The benefits of this approach to anonymity have been outlined above and it has the support of several lived experience consultants involved in the project.

Finally, it is possible that participants may be adopted but not be aware of this fact. This would, of course, mean that these participants would not be eligible for the study. The applicant believes that there is no unobtrusive way to ascertain biological links between participants and parents and acknowledges that this occurrence is possible. However, if an adopted participant has grown up believing that they are biologically related to their parents, it could be argued that their experiences and beliefs about inherited mental or physical health conditions would be very similar to a non-adopted individual.

SECTION FOUR: signature

Applicant electronic signature: Max Homberger
Date 23/5/2017

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review   x☐

Project Supervisor name (if applicable): Suzanne Hodge & Graeme Reid   Date application discussed 23/5/2017

Submission Guidance

1. **Submit your FHMREC application by email to Diane Hopkins (**d.hopkins@lancaster.ac.uk) as two separate documents:

   i. **FHMREC application form.**
   Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*

   ii. **Supporting materials.**
   Collate the **following materials for your study, if relevant, into a single word document:**

      a. **Your full research proposal (background, literature review, methodology/methods, ethical considerations).**
      b. Advertising materials (posters, e-mails)
      c. Letters/emails of invitation to participate
      d. Participant information sheets
      e. Consent forms
      f. Questionnaires, surveys, demographic sheets
      g. Interview schedules, interview question guides, focus group scripts
      h. Debriefing sheets, resource lists

      Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:

i.   Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to **Diane Hopkins by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.

ii.   The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:

   a.   existing documents/data only;
   b.   the evaluation of an existing project with no direct contact with human participants;
   c.   service evaluations.

3.   **<u>You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application</u>**

Appendix 4-A

**Letter from Division of Health Research Ethics Committee
Indicating Ethical Approval for the Project**

Lancaster University

Applicant: Max Homberger
Supervisor: Suzanne Hodge
Department: Health Research
FHMREC Reference: FHMREC17039

13 November 2017

Dear Max

**Re: Experiences of individuals with a parent who has experiences of psychosis or a
diagnosis of schizophrenia**

Thank you for submitting your research ethics amendment application for the above project
for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The
application was recommended for approval by FHMREC, and on behalf of the Chair of the
Committee, I can confirm that approval has been granted for the amendment to this research
project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements
  in order to conduct the research are met, and the necessary licenses and approvals
  have been obtained;
- reporting any ethics-related issues that occur during the course of the research or
  arising from the research to the Research Ethics Officer at the email address below
  (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse
  reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the
  Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

Appendix 4-B

Participant Information Sheet

Version 1

Lancaster University

Participant Information Sheet

Experiences of individuals with a biological parent who has experiences of psychosis or a diagnosis of schizophrenia.

Thank you for expressing your interest in taking part in this research study. Before deciding whether you would like to take part, it is important that we explain why the research is being done and what it would involve. Please take time to read and think about the information provided. Don't hesitate to contact the lead researcher (Max Homberger) via email if you have any questions or concerns. You can also discuss the study in person or via phone/Skype with Max prior to deciding whether you would like take part. The study is part of a doctoral training course and will be submitted as a thesis.

What is the study interested in?

This study is interested in how individuals who have a biological parent who has experiences of psychosis or received a diagnosis of schizophrenia view and make sense of their own mental wellbeing. The study doesn't have any predictions or hypotheses – it is simply interested in learning about your own experiences within your family. We are aiming to interview between 6 to 8 people and then look for similar themes across this group of people.

How did this study come about?

There is already some research interested in what it is like for children to support a parent who is experiencing mental health difficulties. However, there is no previous research looking at how having a biological parent who has experienced psychosis/schizophrenia influences how young and grown-up children view their own mental wellbeing. We are also interested in how people draw on different information about psychosis/schizophrenia in making sense of their own mental wellbeing.

What is the aim of the study?

In addition to focusing on individual experiences, this study will also be taking a critical look at some of the previous research which has influenced how mental health difficulties are viewed in the UK and internationally. The overarching aim of adopting a critical perspective is to see whether there are alternative perspectives to mental health and wellbeing which could be more helpful to individuals and families.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. If you decide not to take part, you will not be contacted again regarding this study. If you agree to take part, you can still stop and withdraw at any time during the interview without giving a reason.

Following the interview, you can still withdraw from the research and the recording will be destroyed. You will be able to withdraw your data from the study at any point up to 14 days after the final participant has been interviewed.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to take part in an interview with Max Homberger. The interview could be done at your own home, or we can arrange another location in the community (such as a room in a library). You would be refunded by Lancaster University for your travel expenses to this location. Alternatively, the interview could be done over telephone or video call (Skype). You should have received a consent form along with this information sheet, please contact Max Homberger if you have not. Before the interview you will be asked to read and sign this consent form (or give verbal consent if the interview was via phone/Skype).

About the interview

The interview will be done on a one-to-one basis, just with yourself and Max in the room. If you would feel more comfortable having somebody else in the room that is completely fine. It is expected that the interview will last between 60 to 90 minutes. The format and questions in the interview will be different for each person. Max will have a few general topics to cover but the conversation will be largely guided by what you choose to discuss. You can choose not to answer any of the questions, or can stop the interview at any time and it can be done in two parts if you get tired. The interview will be recorded and then transcribed (turned into a written version). You will also be asked to provide some information about your age and how you identify yourself culturally (for example: ethnicity, gender, religion, or any other cultural identities which are important to you).

Following the interview

The process of reading and analysing the transcript of your interview will require the researchers read each interview in detail and find important themes. The researcher will then compare these themes across all the transcripts to identify shared themes. This process requires the researcher to make their own interpretations. It is seen as good practice to take these interpretations back to the person who was interviewed to make sure they fit with the original meaning. As with the rest of the study, this part of the research is entirely optional and you can opt into it by ticking a box on the consent form.

Will my data be identifiable?

The information you provide during the interview will be transcribed by Max Homberger. Because direct quotes from your interview may be used in the final paper, your information will not be completely confidential. However, your personal details (such as name, age, address) will not be stored together with your interview transcript.

There are also some limits to confidentiality: if what is said in the interview makes Max think that you, or someone else, is at significant risk of harm, he will have to break confidentiality and speak to the appropriate services about this. If possible, Max will tell you if I have to do this.

Will my information be anonymous?

Yes – the information you supply to the study will be reported anonymously. By default, your transcript and any direct quotes used in the paper will be given a pseudonym. However, you also have the option of coming up with your own pseudonym (you can decide this on the consent form). Your age, cultural information (e.g. gender, ethnicity), and the age and gender of your parent who has experienced psychosis/schizophrenia, will be presented alongside your pseudonym in a table in the final paper.

What will happen with my information?

- o Audio recordings will be destroyed after they have been transcribed and checked.
- o Confidential data will be anonymised by use of a pseudonym.
- o Confidential data will be destroyed once demographic data has been recorded.
- o Demographic information (age, gender, etc.) will be entered into a password protected document. This information will be kept separately from your interview transcript.
- o The files on the computer will be password encrypted (that is no-one other than the research team will be able to access them) and stored online on the University's secure cloud system (called Box).
- o At the end of the study, the written transcripts will be kept securely on the computer for ten years.

What will happen to the results?

The results will be summarised and reported in a doctoral thesis and may be submitted for publication in an academic or professional journal. The results will hopefully be published in an open-access journal, which means anyone will be able to read the final paper free of charge. The results may also be published on a blog or other website and shared on social media (e.g. Facebook, Twitter).

Are there any risks?

There are no risks anticipated with participating in this study. However, taking part in the interview might cause you to experience difficult emotions due to the personal nature of the topic. If you experience any distress during or following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

There are no direct benefits in taking part. However, it is hoped that the results of the study will inform mental health professionals and help people working with both individuals and families.

Version 1

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information? How do I opt in?

If you have any questions about the study, please contact the main researcher:

Max Homberger
Trainee Clinical Psychologist
Lancaster University
Email - m.homberger@lancaster.ac.uk

If you do not wish to speak with Max – you can also contact one of the project supervisors:

Dr Suzanne Hodge
Researcher/Lecturer
Lancaster University
Email – s.hodge@lancaster.ac.uk

Dr Graeme Reid
Consultant Clinical Psychologist
North West Boroughs Healthcare NHS Foundation Trust
Email - Graeme.Reid@nwbh.nhs.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researchers, you can contact:

Professor Bill Sellwood, Chair in Clinical Psychology
Tel: 01524 593998
Email - b.sellwood@lancaster.ac.uk

If you wish to speak to someone outside of the Doctorate in Clinical Psychology Programme, you may also contact the chair of the Faculty of Health and Medicine Research Ethics Committee:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine, Lancaster University, LA1 4YG

Version 1

Resources

It is not anticipated that taking part in this research will cause distress. However, should you feel distressed as a result of taking part you can contact:

Max Homberger from the research team   m.homberger@lancaster.ac.uk

You can also contact your GP.

The following organisations may also provide advice or support.

SANE (www.sane.org.uk/what_we_do/support/helpline)

SANE runs a national, out-of-hours mental health helpline offering specialist emotional support and information to anyone affected by mental illness, including family, friends, and carers. They are open every day of the year from 4.30pm to 10.30pm. Their phone number is 0300 304 7000.

The Samaritans (www.samaritans.org)

The Samaritans offer a non-judgemental listening service. Their phone number is 08457 90 90 90 (charges apply) or you can email them on jo@samaritans.org

If you do not live in the United Kingdom. Max Homberger will make every attempt to identify some suitable organisations for you to contact for support.

Appendix 4-C

Demographic Information Form

Lancaster University

Demographic Information Questionnaire

Age:_____

Gender:_____

Ethnicity:_____

Are there any other important ways you identify yourself culturally?:

_____

Age and gender of your biological parent(s) who has
experienced psychosis or received a diagnosis of
schizophrenia:

Age:_____

Gender:_____

Appendix 4-D

Participant Consent Form

Lancaster University

Consent Form

Study Title: Experiences of individuals with a parent who has experiences of psychosis or a diagnosis of schizophrenia.

We are asking if you would like to take part in a research project looking at the experiences of individuals with a biological parent who has experiences of psychosis or a diagnosis of schizophrenia. Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Max Homberger. You can also contact a member of the research team (contact details on information sheet).

Please initial each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐

2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐

3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐

4. I understand that audio recordings will be kept until the research project has been examined and then destroyed. ☐

5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to 14 days after the final participant's interview. ☐

7. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐

8. I understand that the researcher will discuss data with their supervisor as needed. ☐

9. I understand that any information I give will remain anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this confidential information with their research supervisor. ☐

10. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

11. I would like to be contacted again by the researchers
    to read the analysis related to my interview to make
    sure that it reflects my original meaning.

Your transcript will be anonymised, that is, you will be assigned a pseudonym which will
be used for your transcript and any direction quotations used in the final paper.
However, you also have the option of choosing your own pseudonym. If you would like to
do this, please write your chosen pseudonym below:

12. I consent to take part in the above study:

Name of Participant_____**Signature**_____**Date**

Name of Researcher_____**Signature**_____**Date**

Appendix 4-E

Recruitment Poster

Do you have a biological parent with a diagnosis of

schizophrenia or experiences of psychosis?

If you answered 'yes' and are aged 18-35, you can help us by taking part in a research study titled: Experiences of individuals with a biological parent who has experiences of psychosis or a diagnosis of schizophrenia.

We are looking for people who are fluent English speakers; have not experienced psychosis or received a diagnosis of schizophrenia themselves; and are not currently accessing mental health services.

The study involves taking part in an interview (60 to 90 mins) about your own life experiences. The interview can take place at your own home, or a suitable location of your choice (travel expenses provided); interviews can also be via phone or Skype.

If you are interested in taking part in the interview and would like more information, please contact Max Homberger via email – m.homberger@lancaster.ac.uk

Lancaster University

Appendix 4-F

Topic Guide for Semi-Structured Interviews

Experiences of individuals with a parent who has experiences of psychosis or a diagnosis of schizophrenia

Semi-structured interview schedule

This interview schedule will provide the interviewer with the key topic areas to be discussed during the interview. Possible questions are presented under each topic area. However, questions and topics of the interview will vary depending on how the participant answers the questions. The interviewer will pursue topics and areas which appear to be most important to the participant. The interviewer will aim to conduct the interview in a conversational manner to ensure that the participant feels as comfortable as possible.

The interviewer will follow the language and words used by the participant as closely as possible, avoiding bringing any new language or ideas into the discussion. This will be particularly important for conversations around mental health, and explanations of 'psychosis/schizophrenia'.

Introduction

The interviewer will introduce himself, including his role within the project and research team. An informal, 'warm-up' discussion might be had to help set the participant at ease prior to discussing personal and emotive areas with someone they had only just met. Interviewer and participant will discuss participant information sheet, consent form, and process of the interview. Opportunity to ask questions. Demographic information will be obtained from the participant. Consent form will be collected from participant.

Becoming aware of parent's diagnosis/experiences and experiences/meaning of this

Example questions:

Could you tell me about when you first became aware of your parent's diagnosis/experiences?

What was your first reaction?

How did you learn about this? Who told you?

How was this first discussed with you?

What sense did you make of this at the time?

What did it mean to you personally?

Experiences/understanding of mental health prior to becoming aware of parent's diagnosis

What was your experience of mental health prior to becoming aware of your parent's diagnosis?

Did you have other family members or friends who had experienced similar things? Who?

How was mental health discussed within your family prior to this? What about at school, university, or work?

What had you heard/read through the media or on the internet?

Information participant has been given or sought out about 'psychosis/schizophrenia'

What information were you given about hearing

voices/psychosis/schizophrenia? What information did you seek out yourself?

What did you think about this information? How did you interpret

it? What effect or change did reading this information bring?

Who did you discuss this with? How did you find this discussion?

How participant has viewed their own psychological wellbeing and how this has changed

What experiences have you had with regards to your own mental

wellbeing? How have you made sense of this?

How has this changed over time?

What has influenced how you view your own mental wellbeing? In the past?

Now? How does your family respond to expressions of difficult emotions?

Conclusion

At the end of the interview, or if necessary during the interview, the interviewer will check-in with the participant to ensure that they are not feeling distressed as a result of the interview. If the participant describes feeling distressed, they will be reassured and given information about possible sources of emotional support (available on the participant information sheet).

Appendix 4-G

Participant Debrief Sheet

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Debrief Sheet

Thank you again for taking part in the interview and making this research project possible.

What was the study and interview interested in?

This study was interested in how individuals who have a biological parent who has experienced psychosis or received a diagnosis of schizophrenia view and make sense of their own mental wellbeing. The study didn't have any predictions or hypotheses – we were simply interested in learning about your own experiences within your family. We are aiming to interview between 6 to 8 people and then look for similar themes across this group of people.

How will the results be useful?

It is hoped that this study will influence how mental health services work with biological families where one individual has experienced psychosis or received a diagnosis of schizophrenia. Specifically, the results might help professionals to explain and discuss these difficulties with offspring in a way which is most beneficial for them.

Sources of support

Taking part in an interview about personal and emotive topics can be upsetting or bring up difficult emotions, this is understandable and very normal. If you do feel distressed and don't feel comfortable discussing things with friends or family, there are contact details for some free helplines on the information sheet. Alternatively, you can always make an appointment to talk with your general practitioner (GP) or register with your local GP clinic if you don't have one.