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**FAMILY EXPERIENCES OF APPROACHES FOR PSYCHOSIS
THAT INCLUDE THE FAMILY**

Section A: What does the research tell us about family experiences of family interventions for psychosis?

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Summary of Major Research Project

Section A:

This literature review investigated qualitative research that explored family experiences of interventions for psychosis that include the family. There are various family approaches for psychosis experiences that incorporate aspects of systemic, psychoeducational and open dialogue interventions. Eleven studies were included and thematic synthesis was used to identify themes: sharing, Increased understanding, A change/ shift, Clinician attributes, Coping and Challenges. Findings showed that families felt they benefited from an intervention with a family approach. The intervention that families participate in can shape the lens by which they view the difficulties of their family member.

Section B:

This project explored experiences of family members who had attended an adapted open dialogue approach in an early intervention for psychosis service within the NHS. Seven participants who had attended three open dialogue informed network listening meetings were interviewed and an interpretative phenomenological analysis was used to analyse data. Findings illustrate four experiential themes ‘as a family as a whole’, talking that otherwise wouldn’t happen, making sense together, relationship to help. Participant experiences were positive overall but it would be beneficial to explore experiences of those who have previous experiences of mental health services.

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Amber Iszatt

Section A

**What does the research tell us about family experiences of
family interventions for psychosis?**

Word count: 7912 (8213)

Abstract

Introduction: Research has demonstrated good outcomes for family approaches for psychosis and they are recommended in NICE guidelines. There are various family approaches for psychosis experiences that include systemic, psychoeducational and open dialogue interventions. These approaches all include the family but differ in their theoretical underpinnings. Research is growing in this area but has yet to explore the family experiences of varying approaches. What is valued in such approaches will broaden understanding to interventions that include families and carers.

Methodology: Qualitative studies were included that explored family experiences of an intervention for psychosis that directly involved the family. Studies were searched from PsycINFO, Web of Science, ASSIA and PubMed. Eleven studies met eligibility criteria.

Literature review: A thematic synthesis was conducted, identifying six themes: (1) Sharing (sub-themes; sharing multiple perspectives, things that wouldn't have been shared elsewhere, sharing responsibility) (2) Increased understanding (sub-themes; knowledge and understanding of mental health, understanding of experiences), (3) A change/ shift (sub-themes; in family response and expectations, communication, in feelings about the situation, in relationships to services and within the family), (4) Clinician attributes, (5) Coping (sub-themes; family support, skills, independence), (6) Challenges (sub-themes; emotional, logistic).

Clinical and research implications: Findings indicate how families of individuals who experience psychosis benefit from involvement with their care. The intervention that they participate in can shape the lens by which the family view the individual's difficulties.

Keywords: Psychosis, Family interventions, open dialogue

Introduction

The diagnostic umbrella of ‘psychosis’ will be used in this review. This review looks at family approaches (FA) that have taken place within mental health services where the term ‘psychosis’ has been used to describe an individual’s experiences which has allowed them to access the service. The term ‘psychosis’ describes a clinical construct comprised of other constructs used to denote experiences, variously described as hallucinations, delusions, disorganised speech, social withdrawal and loss of motivation (Gaebel & Zielasek, 2015).

There are differing approaches to mental health. The Diagnostic and Statistical Manual of Mental Disorders (The DSM-5) (The American Psychiatric Association, 2013) uses categorical classification systems to aid in diagnosing disorders to summarise “symptoms” experienced by individuals. There are critiques to this medical understanding of mental health such as for pathologising understandable human experiences and perpetuating stigma (Seery, Bramham & O’Connor, 2021). “Psychosis” is often perceived as biological by the general public, whereas it has been suggested that depression and anxiety are responses to hardship (for example, acknowledging that a situation is depressing) (Higgs, 2020).

An alternative to a medical model of mental health is to focus on psychological formulation behind an individual’s distress that considers the context of their social circumstances, relationships and significant life events. The Power Threat Meaning framework provides a structure for this (Johnstone et al., 2018). Within this framework, experiences such as hearing voices may be thought of as reactions to a very stressful environment. There is extensive evidence that psychosis is a response to traumatic experiences and predominantly linked to adverse child experiences (Longden & Read, 2016; Read et al., 2014). For example, a meta-analysis carried out by Varese et al. (2012) illustrated an increased likelihood of developing psychosis if an individual has experienced childhood adversity and trauma which further increases with cumulative adverse experiences. The evidence-based traumagenic neurodevelopmental model of psychosis suggests that trauma in early years leads to

neurodevelopmental brain changes that increase sensitivity to further stress, particularly of an interpersonal nature (Read et al., 2001; 2014).

Interventions for psychosis in the UK

In the United Kingdom (UK) it is recommended that individuals who experience psychosis are offered individual cognitive behavioural therapy for psychosis (CBTp) and a family intervention (FI) (NICE, 2014). Family members play a vital role in care of an individual experiencing psychosis. Families can support pathways into services (Del Vecchio et al., 2015) and having a family member involved in services can increase the likelihood of engagement (Stowkowy et al., 2012). Furthermore, when a family member experiences psychosis, the family judgments and understandings of the situation as well as the carer resources are crucial in the outcomes of the service user (SU) and carers (Kuipers et al., 2010). Carers may also notice differences and warning signs of increased distress and changes in presentation (Worthington et al., 2013).

The NHS Long Term Plan (2019) has placed emphasis on increasing training in FA due to its considerable economic advantages. Findings from two systematic reviews suggested that FA reduced hospital admissions, recurrence of severe difficulties and difficulties with functioning such as social functioning (Pharoah et al., 2010; Camacho-Gomez & Castellvi, 2020). FA have also been shown to support the needs of carers (Sellwood et al., 2001).

Family approaches for psychosis

FA for psychosis vary in how they are carried out, but fundamental aspects of interventions within the evidence base include psychoeducation, collaboration with family members, and interventions to improve communication, problem solving and coping within families (McFarlane, 1991; Onwumere, 2011). Kuipers (2006) proposed a focus of FA to be on family interaction, with an emphasis on replacing stress, anxiety, and criticism with problem solving and tolerant reappraisals. A previous systematic review that looked into the process of

FA suggested that the vital active components of a family intervention for psychosis were having a supportive therapeutic relationship, education about “the illness” and development of coping skills (Gracio, Goncalves & Leff, 2015).

Some authors have situated the research evidence on high expressed emotion (EE) within the stress-vulnerability model of mental health. EE is a measure of attitudes, emotions and behaviours expressed by families/ carers. The family environment is a key element to significant stress levels for individuals with psychosis experiences and high EE influences reoccurrence of severe difficulties. The stress-vulnerability model proposes that the individual and their caregivers reciprocally influence each other which contributes to stress and the vulnerabilities of the other (Amaresha & Venkatasubramanian, 2012).

Some FAs fundamentally take a psychoeducational approach. They acknowledge that individuals with severe mental distress often depend on families and that those families would benefit from knowledge about ‘psychosis’ and ‘symptoms’, medication and skills to help with coping, management and noticing signs of ‘relapse’. Skills based approaches focus on the idea that high EE can lead to recurrence of mental distress and that problem solving strategies and improved communication skills can support practical difficulties within the family (Kuipers et al., 2006).

Other interventions use a systemic approach in recognising that processes within the family influence the individual experiencing distress; interactions, patterns and changes within the family are identified and thought about, questioned and reframed (Lincoln & Pedersen, 2019). Interventions often use elements of these approaches in diverse ways.

Systematic reviews on FA such as Pharoah et al. (2010), Camacho-Gomez and Castellvi (2020), Solmi et al. (2022) have specifically looked at quantitative outcomes such as relapse rates, hospital duration, medication compliance, employment status, symptoms, quantitative measures of quality of life, scores and changes in family burden and EE. As

previously mentioned, Gracio et al's. (2015) systematic review included qualitative studies and utilised content analysis to explore the active ingredients within the process of FAs. This study however, looked at core ingredients that were present in the specific interventions they investigated (interventions that included psychoeducation and coping skills). Family experiences of differing interventions have not been explored. Key elements of education and coping skills, fundamentally differ from an open dialogue approach, discussed next, which was an approach not included in that review.

Open dialogue (OD) is a less prevalent but growing approach for individuals with experience of psychosis and other severe forms of mental distress. It is described by Bergstrom et al. (2018) as a “family-oriented early intervention approach”; the intention is to begin working with an individual experiencing severe mental distress within their social network within twenty-four hours. The network includes the SU, family, anyone important to them and professionals they are involved with. Meetings focus on dialogical communication, where transparent, therapeutic communication and dialogue allows meaning to be constructed by language. This approach differs profoundly from other family approaches for psychosis in the theoretical assumptions in that it privileges the wisdom of the members of the social network and the identified SU rather than that of clinicians. Consequently, the family are not seen as an object of treatment; the network are viewed as partners in the process (Seikkula & Olson, 2003). Professionals are a part of the network and can reflect on their personal emotional responses through their reflections (2003). The approach also avoids a leap to diagnostic labelling or explanations of the issue as ‘illness’, and a reduced reliance on medication. There is a developing evidence base for positive outcomes long term that include decreased hospital duration and increased return to education or work (Bergstrom et al., 2018; Seikkula et al., 2003; Seikkula et al., 2006). There is also emerging evidence that OD has positive long-term outcomes for younger people aged 13-20 (Berstrom et al., 2022).

Exploration of the literature for this introductory section led to identification of three main family approaches. Table 1 shows the main points of similarity and difference between them.

Table 1

	Psychoeducation groups	Family interventions (FI) as recommended by NICE (2014) within the NHS	Open Dialogue
Epistemological underpinning	Positivism	Positivism	Social Constructionism
Timing and session number	Not specified	Timing not specified but at least ten sessions to be carried out for between three months to a year is recommended.	Recommended that first meeting takes place within 24 hours of the crisis, frequency and duration of meetings are flexible and decided by the network, meetings occur for as long as required (weeks/ months/ years).
Who is involved	Multifamily groups that can include the service user and their relatives or just the relatives without the service user (often carers).	The family and the service user.	The social network (anyone in the service user's network that they wish to attend including family, friends, professionals involved with their care and other agencies involved with their care).
Approach	Can utilise elements of cognitive-behavioural theory. Information about psychosis from a biomedical lens is shared. Sometimes information sharing is also combined with sharing of skills to encourage problem solving and communication skills.	Can utilise cognitive-behavioural theory and a systemic framework. Information about psychosis from a biomedical lens is shared. Problem solving and supportive ways of communicating is encouraged. Varying elements of systemic approaches are used in different services; often there is a premise to promote changes in interactions through systemic questioning and reframing, identifying patterns and processes in communication (e.g. Retzer, 2004).	Utilises systemic theory alongside dialogical theory and psychodynamic principles. Open dialogue is a way of both structuring the service at an organisational level and a therapeutic approach (Seikkula et al., 2003). There is a focus on understanding the meaning of the experiences through language. Communication and decisions are transparent and all take place within the network. No preformed plans or hypotheses are made; the aim is to create meaning through dialogue, not to find explanations.
Role of professional	Educational/therapeutic/ expert in relation to psychosis.	Educational/therapeutic/ expert in relation to psychosis.	Therapeutic. Refraining from imposing diagnosis/ illness model. Professionals are a part of the network.

			Reflections are shared (but not explanations). Power imbalances are addressed due to decisions being made transparently and by the whole network (not the professionals).
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Exploration of family member experiences of different FAs is important to see which aspects are valued in different approaches. Byrne et al. (2020) have commented that qualitative research on SU and family experiences of interventions for psychosis is primarily focussed on experiences of antipsychotics. However, there is a growing body of qualitative research looking at social interventions which is timely for this review. Due to a lack of qualitative reviews, and varying approaches to family interventions, this review looked at family/carer experiences of a range of family approaches for working with people with experience of psychosis.

Rationale

There are limits to the support mental health services can provide and families often become involved with supporting their family members who experience severe mental distress. There are good outcomes for family interventions. The aim of this review was to identify a range of self-reported family and carer experiences of varying family interventions (that do not all have the key ingredients drawn out in a past review) to broaden understanding of why approaches that include family members might be helpful and what is most valued by them.

Method

Inclusion and Exclusion Criteria

Experiences of any intervention within a service that supported people with psychosis experiences that incorporated the family was included. In this review FAs refer to interventions that are varying in nature. Papers were included if they were qualitative.

Papers that focussed on exploration of the family experience of the service in general were excluded, even if the service offered FAs. If the family were unable to share much about their experiences (e.g. a focus on quantitative measures with a few lines available for qualitative feedback), the studies were not included.

Table 2

Summary of inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • The intervention took place in a service that supports individuals with psychosis • The intervention includes families and/or carers • The study was a qualitative study • The study explored family and/or carer experiences 	<ul style="list-style-type: none"> • Studies that explored general experiences of families and did not have any specific questions or exploration of FA • Studies with quantitative outcomes and minimal qualitative information

Search strategy

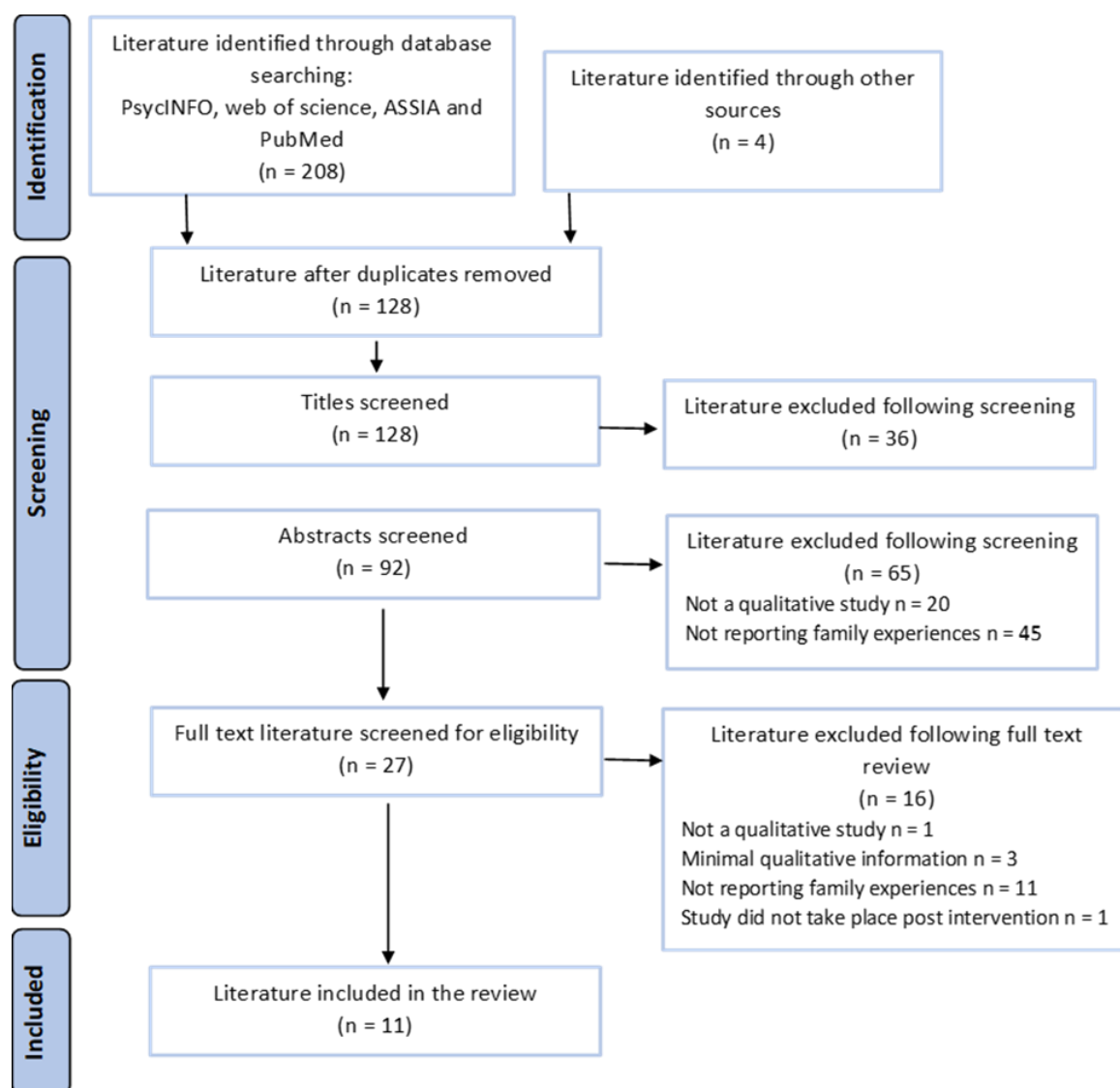
In October 2022 PsycINFO, Web of Science, ASSIA and PubMed were used for a search of the literature. The search terms used were "family intervention" or "open dialogue" AND psychosis AND qualitative OR synthesis OR narrative OR interview* OR experience* OR hermeneutic OR phenomenol* OR grounded OR discourse*. The reference sections from existing reviews were also looked at and a Google Scholar search was conducted to identify any relevant missing papers. Two hundred and twelve papers were identified. After duplicates were removed, remaining papers were screened by carefully reading titles, abstracts and full texts.

Additional search terms were used when initially searching (e.g. “schizophrenia”) but this increased the number of returns to an unmanageable degree, and a check of these showed them to be largely irrelevant.

A total of eleven papers were found to be appropriate for the review. The search strategy is illustrated in the flow diagram below, following the guidance from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Figure 1).

Figure 1.

PRISMA diagram of systematic literature search guidance provided by (Moher et al., 2015).



The studies that were in this review included three different interventions: the conceptualisation of FI (as stated above in NICE guidelines within the NHS) which can utilise both psychoeducation and cognitive behavioural theory within a systemic framework; psychoeducation groups which utilise cognitive behavioural theory; and OD which utilises elements of systemic theory with dialogical theory and psychodynamic principles.

Structure of review

Key information from each study has been summarised and presented in Table 2. This review will begin by summarising a combined description of the included studies followed by an assessment of quality focussing on methodology. The next section will present synthesised findings using a thematic synthesis (Thomas & Harden, 2008) which is appropriate to synthesise qualitative research methods of varying kinds (Braun & Clarke, 2006). Finally, conclusions and clinical implications will be discussed.

A quality appraisal of the studies was completed using ‘The Critical Appraisal Skills Program’, as per recommendations for a systematic review (Hannes, 2011). The Qualitative Studies Checklist was used (CASP; Long et al., 2020) to guide the appraisal (Appendix A). This tool highlights the methodological rigour of studies, whilst also considering clarity, clinical contribution and the reflexivity of the researcher. CASP tools are reportedly succinct and effective in addressing aspects needed to critically appraise evidence and are endorsed by Cochrane and the World Health Organisation for qualitative syntheses (Noyes et al., 2018; Long et al., 2020).

Results

Overview of studies

Eleven studies met criteria for this review (See Table 3 for study details mentioned in this section). Ten studies were published in English and one was published in Norwegian with an option to translate. All studies explored family or carer experiences of FA within a mental

health service in the community. No studies that met inclusion criteria took place in inpatient settings. Services included family support services, community mental health teams, early intervention services and a mental health and rehabilitation service. Most studies had participants who had been receiving support for a first episode of psychosis, but some did not specify; one study had a variety of participants who had used mental health services for a varying number of years and thus was not specific to those who had experienced a first episode.

The type of intervention varied as well as the country where this took place. Four interventions that were described as “FI” all took place in the UK. Two of these described the intervention as drawing from both systemic family therapy and cognitive behavioural approaches, one described utilising a cognitive behavioural model (as described by Barrowclough and Tarrier, 1992) and one did not specify which approaches their intervention drew from. Four interventions were psychoeducation groups, one of which had individual sessions with family members and SUs beforehand to build a therapeutic alliance. Three of these took place in Norway and one took place in Israel. One of these studies was a randomised control trial that carried out either a psychoeducation group for parents or a group that focussed on therapeutic alliance. A study in Australia used OD as the intervention and two studies in the United States of America utilised OD informed interventions. All participants in these studies were adults apart from one study which looked at young people (age 15-19). All interventions included the SU in sessions apart from one parent group intervention.

All studies in this review, apart from one, gathered data using semi-structured interviews (one described unstructured interviews), although one study additionally utilised observations and recordings of the family sessions. The papers varied in their method of data analysis but ultimately the results sections all generated themes. Five papers used thematic analysis (two specified that this was via a systematic text condensation approach) and one used thematic content analysis. One study used Framework analysis. One study utilised

Interpretative Phenomenological Analysis, another described using “A Phenomenological approach” combined with open coding and another utilised Lindseth and Norberg's (2004) phenomenological-hermeneutic approach. One study used a grounded theory approach.

One OD study interviewed seventeen participants as a network, in keeping with the OD approach and so the numbers of family members are not specified (Florence et al., 2021). From the studies that specified numbers, there was a total of 209 family members/carers who shared their experiences of family interventions. Family members and carers included parents, siblings, partners, grandparents, and an aunt.

Table 3

Summary of main characteristics of studies.

Authors and Country	Study	Sample	Type of intervention and service	Design and Measure	Analysis	Key findings
Buus & McCloughen (2021) Australia	Client and Family Responses to an Open Dialogue Approach in Early Intervention in Psychosis: A Prospective Qualitative Case Study	Service users in treatment for first episode of psychosis (n=4), members of their social network (n=14), clinicians (n=10)	Open Dialogue in an Early intervention in Psychosis team First episode of psychosis.	Qualitative, Audio recordings and observation of network meetings alongside semi-structured interviews of experiences of open dialogue	Thematic analysis	Families appreciated OD for its transparency and its ability to provide a space they otherwise would not have in supporting family communication and improved understanding. Support, overall, was strengthened. Collaboration in communication and thinking alongside the reflective nature helped it feel less judgmental, less prescriptive and labelled. It was helpful hearing personal thoughts of clinicians. Meetings were difficult practical and emotional work. One family found it frustrating that diagnostic labels were not used.
Byrne, Bird, Reeve, Jones, Shiers, Morrison & Peters (2020) UK	Understanding young peoples' and family members' views of treatment for first episode psychosis in a randomised controlled trial (MAPS)	Service users (n=13), family members (n=18); 17 parents and 1 grandmother	FI within the MAPS trial (Managing Adolescent first Episode Psychosis)	Qualitative semi-structured interviews	Thematic analysis	Themes that arose indicated that experiences included creating a safe space to express concerns, sharing of perspectives, communication surrounding what people have been doing right and wrong. Improved understanding included positive change in communication and increased support. Difficulties included anxiety to share, emotional distress to hear experiences of the service user and practical issues such as finding time.

Florence, Jordan, Yasui, Cabrini, Davidson (2021) USA	“It Makes us Realize that We Have Been Heard”: Experiences with Open Dialogue in Vermont	Service users and families n=17 (families and services users were interviewed as a network, similarly to the OD approach and so numbers are not specified)	Open dialogue informed practice known as Collaborative Network Approach, A variety of participants who had used mental health services for a varying number of years (not specific to those who had experienced a first episode).	Qualitative, individual unstructured interviews	A Phenomenological approach (combined with open coding)	Findings suggest that elements of OD are flexible, person-centred, encourage processes of negotiation, foster share decision making and highlight the importance of family and social supports in care. The presence of the network was experienced by families as a way to reduce stigma, validate concerns, access multiple perspectives, decide together, understand others, slow things down, create language to describe conflict and work towards collective understanding. A key aspect was reflections.
Gidugu, Rogers, Gordon, Elwy, Drainoni (2021) USA	Client, family, and clinician experiences of Open Dialogue-based services.	Service users (n=6) family members (n=10) included one or both parents, a sibling, an aunt.	Pilot study of an adapted open dialogue model named Collaborative Pathway within a large mental health and rehabilitation service. Following a first episode of psychosis.	Qualitative semi-structured interviews	Thematic analysis	Themes within the findings illustrated experiences of it being a positive contrast to other treatment experiences, feeling supported, collaboration in being non-hierarchical, shared agendas, sharing of ideas from all, transparency and openness (specifically not feeling judged and hearing the clinicians perspectives), processing experiences, reflections, family involvement and multiple understandings
Jensen, Carr, Degnan, Berry, & Edge (2021) UK	Exploring service user and family perspectives of a Culturally adapted Family Intervention (CaFI) for African-Caribbean people with	Service users (n=22) Parents (n=12)	Culturally adapted FI (CaFI) Those with schizophrenia or other related diagnoses from community and mental	Qualitative semi-structured interviews	Framework analysis	Family members’ perceived benefits were: increased knowledge and understanding of diagnosis, improved communication and relationships, improved coping with their family member’s stress. Therapists were viewed as supportive and competent,

	psychosis: A qualitative study		health services in a trust in North England.				content was experienced positively with some suggestions (more on relapse prevention and some support with anger), delivery of therapy was seen positively (flexibility of time and day and location).
			Not specified whether this was following a first episode of psychosis or longer term difficulties.				
Levy-Frank, Hasson Ohayon, Kravetz & Roe (2012) Israel	A Narrative Evaluation of a Psychoeducation and a Therapeutic Alliance Intervention for Parents of Persons with a Severe Mental Illness	The paper says that service users had a diagnosis of a 'Severe mental illness' Groups; Parents in the psychoeducation intervention (n=53) in the therapeutic alliance intervention (n=40)	Psychoeducation or therapeutic alliance groups for parents Parents only. Their son or daughter had a diagnosis of a "severe mental illness", it is not specified how long they have had this.	Semi structured interview (The Narrative Evaluation of Intervention Interview), following an RCT	Grounded theory analytic approach		One group focused on providing knowledge and improving communication and coping styles, and the other focused on relationships and social support. Themes did not differ between groups and included: increased knowledge, positive changes in coping, feelings of support, positive changes in the family (communication, cooperation, understanding), changes in self-perception (more equipped), changes in perception (and emotional perception) towards their child, social changes. The helpfulness of the group and therapeutic process (e.g. providing of materials, empathy) was also identified.
Nilsen, Frich, Friis, Røssberg (2014)a Norway	Patients' and Family Members' Experiences of a Psychoeducational Family Intervention after a First Episode Psychosis: A Qualitative Study	Service users (n=12), family members (n=14)	Family Intervention (psychoeducational) Multi-family or single-family group intervention. Following a first episode of psychosis.	Qualitative, semi-structured interviews	Thematic analysis (using a systematic text condensation approach)		Six themes were identified: alliance, support, anxiety and tension, knowledge and learning, time, and structure. Reduced feelings of shame and increased hope for the future was reported but experiences of anxiety were also reported.

Nilsen, Frich, Friis & Norheim (2014)b Norway	Participants' perceived benefits of family intervention following a first episode of psychosis: a qualitative study	Service users (n=12), family members (n=14)	Family Intervention (psychoeducational), multi-family group intervention or single family intervention. Following a first episode of psychosis	Qualitative, semi-structured interviews	Thematic analysis (using a systematic text condensation approach)	Benefits were grouped into five categories: developing insight, acceptance, understanding and recognising need for support; recognising warning signs; improving communication skills; Learning to plan and problem solve; becoming more independent.
Norheim, Nilson & Biong (2015) Norway	Psychoeducational multi-family groups are recommended in new national guidelines for the treatment of psychotic disorders: What experiences do the participants have?	Parents (n=5) Service users (n=3)	Psychoeducation family intervention groups which include an alliance stage of at least 3 meetings with group leaders and family members (without service user) and conversations with the service user before joining the group Service users had mental health difficulties for several years	Qualitative, semi-structured interviews	Lindseth and Norberg's (2004) phenomenological-hermeneutic approach	Themes described: Increased understanding and knowledge about what the service user is/has experienced, family contribution, psychoeducation which was considered too late into the journey of service use, security in the group, relationship changes with improved openness within families and positive relationships with facilitators. A way forward reportedly could be seen.
Rapsey, Burbach & Reibstein (2016) UK	Exploring the process of family interventions for psychosis in relation to attachment, attributions and problem-maintaining cycles: an IPA study	Parents (n=7) Sibling (n=1) Service users (n=2)	FI in an family intervention service. Not specified how long the service user had experienced mental distress for, although the service often sees individual after a first episode.	Qualitative semi-structured interviews	Interpretative phenomenological analysis	Themes constructed: A supportive therapeutic relationship and safe therapeutic space, identifying when family relationships become unhelpful and patterns of relating, making sense of psychosis and developing a sense of agency.

Stanbridge, Burbach, Lucas & Carter (2003) UK	A study of families' satisfaction with a family interventions in psychosis service in Somerset	Parents (n=17) Partners (n=2) Siblings (n=2) Clients (n=4)	FI in an family intervention service. For families with a family member with presence of psychotic symptoms. Not specified how long the service user had experienced mental distress for, although the service often sees individual after a first episode	Qualitative semi-structured interviews	Thematic content analysis	Satisfaction was related to supporting families with coping with problems and symptoms, improved communication in the family and better liaison with the services as well as feeling listened to. Other factors such as a positive therapeutic and regular evaluation of the usefulness of sessions.
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General critique of studies

A summary of the modified CASP appraisal is presented in Appendix B and fundamental methodological issues are discussed below. A second person looked at two of the papers and there was discussion on agreement of ratings to increase reliability.

Table 4

Summary of CASP appraisal. Green yes, orange partial, red no.

First author	Buus & McCloughen (2021)	Byrne et al. (2020)	Florence et al. (2021)	Gidugu et al. (2021)	Jensen et al. (2021)	Levy-Frank et al. (2012)	Nilsen et al. (2014) ^a	Nilsen et al. (2014)b	Norheim et al. (2015)	Rapsey et al. (2016)	Stanbridge et al. (2003)
Approach (open dialogue, family intervention, psychoeducation)	OD	FI	OD	OD	FI	PG	PG	PG	PG	FI	FI
Aims clear?	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Qualitative methodology appropriate?	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Research design justified?	Orange	Green	Green	Orange	Green	Orange	Orange	Orange	Green	Green	Orange
Appropriate sampling strategy and description of recruitment?	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Data collection method described appropriately?	Orange	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Researcher reflexivity addressed?	Red	Red	Red	Red	Red	Red	Red	Green	Orange	Green	Red
Ethical issues addressed and approved?	Green	Orange	Orange	Red	Green	Orange	Orange	Orange	Green	Orange	Green
Data analysis sufficiently rigorous?	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Clear statement of findings?	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Value of research considered?	Green	Green	Green	Green	Green	Green	Orange	Orange	Orange	Green	Green

Aims and Design

All eleven studies clearly stated their aims as exploring family experiences. This was often explained as being due to minimal exploration of experiences of these interventions in particular services and countries; some of the approaches were newer within the research base (such as OD or culturally adapted FI) or simply because a lot of research focuses on medication and less on psychosocial interventions. Some studies specified some specific areas to explore; Nilsen et al. (2014a), Rapsey et al. (2016) and Stanbridge et al. (2003) were interested in

perceived outcomes such as benefits of the intervention or relational changes that occurred due to the intervention. Byrne et al. (2020) and Jensen et al. (2021) were interested in thinking about the feasibility and acceptability of the interventions. Nilsen et al. (2014b) specifically considered learning from their study for future interventions. Most studies described lack of qualitative research of FA and studies such as Levy-Frank et al. (2012) and Nilsen et al. (2014b) pointed out that qualitative research can help with future development and implementation of interventions.

Although the qualitative design made sense for all of the research aims which centered around exploration of experiences, six studies did not justify why they chose the method used (Buus & McCloughen, 2021; Gidugu et al., 2021; Levy-Frank et al., 2021; Nilsen et al., 2014a; Nilsen et al., 2014b; Stanbridge et al., 2003). Norheim et al. (2015) and Rapsey et al. (2016) explained that their phenomenological methodologies explored subjective experiences and meaning given to these. Florence (2021) gave a less detailed explanation of a phenomenological approach but specified an interest in gathering a deep understanding of subjective experiences. Byrne et al. (2020) gave less description but explained that they wanted to uncover the immediate meaning and thematic representation of participant views and Jensen et al. (2021) clearly described why framework analysis was chosen instead of thematic analysis.

Recruitment strategy

All studies had appropriate recruitment strategies, which appeared opportunistic with researchers or clinicians asking all families who had participated in the specific intervention if they would participate. All studies explained where participants were recruited from and specified numbers of participants (Florence et al., 2021 was unable to specify which were family members or SUs due to the network approach used).

Something to note is that this way of recruiting families who have engaged with the intervention and have agreed to participate in being interviewed might lead to selection bias as

they may feel more favourably towards the intervention or mental health services. They also likely completed a significant amount of the intervention compared those who did not feel favourably towards it (Etikan et al., 2016).

Although recruitment strategy was adequate according to the checklist, demographic information was an area of weakness for some studies where this was not included. Other than Jensen et al.'s (2021) focus on adaptations for cultural differences, the research lacks an ability to illuminate how these approaches are received amongst varying cultural groups. Studies carried out by Buus and McCloughen (2021), Florence et al. (2021), Levy-Frank et al. (2021), Stanbridge et al. (2003) do not mention ethnicity at all. Gidugu et al. (2021) and Rapsey et al. (2016) acknowledge that their studies were limited to all white participants, with Rapsey et al. (2016) also acknowledging that just under half of their sample were from the same family. Some studies acknowledge that their research is not generalisable to wider populations and may be specific to that particular intervention (and some do not) but all studies indicate that further research is needed to better understand experiences of various family interventions.

Ethical considerations

All studies apart from Gidugu et al. (2021) stated that they had received ethical approval from an ethics committee. All studies state that they obtained consent from participants. Three studies specified that they explained to participants identifiable information would be anonymised (Buus & McCloughen.,2021; Jensen et al., 2021; Norheim et al., 2015) and although Byrne et al. (2020, p.3) mentioned confidentiality, they did not specify what the "bounds of confidentiality" were. Rapsey (2016) and Stanbridge (2003) changed names in the study but did not indicate that they shared with participants that their information would be confidential and the other studies did not mention anonymity at all. Ethical issues were therefore not fully addressed according to the checklist because issues raised by the study (such as around informed consent or confidentiality and effects of study participants) were only

satisfactorily addressed by Buus & McCloughen (2021) Jensen et al. (2021) and Norheim et al. (2015).

Data collection and reflexivity

The form of data collected was clear, with most studies utilising semi-structured interviews. Only two studies (Rapsey et al. 2016; Norheim et al. 2015) acknowledged reflexivity, with overall limited acknowledgment of the position and role of the researcher and any possible biases when carrying out data analysis. Reflexivity plays a vital role in the analysis of qualitative data (Shaw, 2010). Potential bias amongst researchers was not acknowledged by any paper. Authors often worked within the service as clinicians or stakeholders which is important to consider.

The specific interventions varied and are unlikely to be exactly replicated due to not being manualised and being carried out by different facilitators impacting the generalisability of findings.

Analysis and findings

All studies apart from one detailed the steps taken within their analysis. Stanbridge et al. (2003) described how their analysis was carried out, only referring to an initial thematic content analysis by the first author and then explaining that this was reviewed a year later by both first and second authors. They shared that there was a reported high level of agreement but did not acknowledge how this was decided and at what stage. Buus and McCloughen (2021) collected audio data from sessions as well as interviews and it was not clear how this was combined.

Studies varied in their acknowledgement of credibility and trustworthiness of the analysis process; clarity in the steps of analysis would be helpful to understand this further. Byrne et al. (2020) explained the steps taken to increase the trustworthiness of the analysis with the involvement of a core analysis team and a wider analysis team who participated in analysis

and development of themes. This team included individuals with personal or parental experiences of psychosis-spectrum difficulties. Jensen et al. (2021) explained why the framework analysis increases credibility and how researcher triangulation was used with analysis being conducted by several researchers and compared. The wider study that these researchers were a part of also led to development of quantitative acceptability ratings. Levy-Frank et al. (2012) utilised the opening step of a grounded theory approach with steps used in content analysis in rating presence or absence of themes to assess inter-rater reliability for categorical ratings which was reported as moderate-high.

Florence et al. (2021) explained that all authors independently read narratives and then met to jointly establish themes although bias was never mentioned. This was similar to Gidugu et al. (2021) who also did not reference bias when describing independent coding of transcripts and joint reviewing to arrive at codes. Buus and McCloughen (2021) alluded to having more than one person analysing the data but did not specify whether this was the case or how they acknowledged bias or credibility in their process. They also utilised multiple data sources but did not recognise triangulation of data nor give detail on this process. Nilsen et al. (2014a) referred to two authors discussing codes and meanings until consensus was agreed but did not elaborate or refer to bias or credibility. Nilsen et al. (2014b) said that codes and units were discussed in a research group but did not elaborate. Norheim et al. (2015) did not refer to who was involved in analysis. Rapsey et al. (2016) ensured to send a summary of themes to participants to confirm this represented their discussions and the first author also engaged in a reflective journal and supervision as a part of the process.

In all studies, quotations were provided and clearly contributed to understanding of the themes. Buus & McCloughen (2021) provided two data extracts but it was less clear how findings were derived from the data. Byrne's (2020) study also looked at experiences of CBT and antipsychotic medication and so the findings of FI were not as detailed as other studies.

Most studies did include discussion of the implication of findings regarding existing and future research. For example, Florence et al. (2021) acknowledged that the findings had agreement with previously found positive experiences of family involvement and added to evidence against the idea of power imbalances in situations where a family member is in crisis. They also suggested that further research is required to understand the mechanisms behind the positive experiences of OD approaches and specifically adding to approaches that may not require long-term use of medication. They also suggest future research should include those who experience these approaches negatively. Three studies did not specify implications of their studies or consider past and future research (Nilsen et al., 2014a; Nilsen et al., 2014b; Norheim et al., 2015) but did describe themes that suggested that the intervention (psychoeducation groups) would be helpful for individuals and their families when there is an experience of psychosis (particularly early on into this process).

Summary

Despite some limitations, studies were appropriate in addressing clear research aims and describing experiences of families. Where there are shortfalls, it also could be hypothesised that word limits in journal articles could have limited the amount that was reported. Valuable research contributions were offered in an area of research where there are few qualitative studies. Studies overall are not very generalisable but the research will be synthesised thematically below.

Data synthesis

As referred to earlier, thematic synthesis was used to synthesise the qualitative data. Papers were firstly read several times to increase familiarity. This review then followed the recommended stages advised by Thomas & Harden (2008). Results sections were coded line-by-line. If text represented family experiences of the intervention then a word or phrase was decided on to summarise this. These codes were then grouped together to form themes for

individual studies. Themes from each paper were then reviewed together to look for similarities and sub-themes to be generated. Sub-themes were then examined to generate main themes.

Findings

The findings relating to family experiences of FA have been grouped into six themes (See table 5) and themes present in each study are presented in table 6.

Table 5

Table showing themes and sub-themes of findings

Themes	Sub-themes
Sharing	Sharing multiple perspectives Things that wouldn't have been shared elsewhere Sharing responsibility
Increased understanding	Knowledge and understanding of mental health Understanding of experiences
A change/ shift	In family response and expectations Communication In feelings about the situation In relationships - To services - Within the family
Clinician attributes	
Coping	Skills Family support Independence
Challenges	Emotional Logistic

Table 6

Table showing study contributions to study themes

		Bus & Mc Cloughen (2021)	Florence et al. (2021)	Gidugu et al. (2021)	Byrne et al. (2020)	Jensen et al. (2021)	Rapsey et al. (2016)	Stanbridge et al. (2003)	Levy-Frank et al. (2012)	Nilsen et al. (2014) ^a	Nilsen et al. (2014) ^b	Norheim et al. (2015)
	<i>Approach (open dialogue, family intervention, psychoeducation)</i>	OD	OD	OD	FI	FI	FI	FI	PG	PG	PG	PG
Sharing	Multiple perspectives	✓	✓	✓	✓	✓	✓	✓	·	·	✓	✓
	Things that wouldn't be shared elsewhere	✓	✓	·	✓	·	✓	·	✓	✓	·	·
	Shared responsibility	✓	✓	✓	·	·	·	·	·	·	✓	✓
	Shared experiences	✓	✓	✓	✓	✓	✓	·	✓	·	·	✓
Increased understanding	Knowledge and understanding of Mental health	·	·	·	·	✓	✓	✓	✓	✓	✓	✓
	Understanding of experiences	✓	✓	✓	✓	·	✓	✓	✓	✓	✓	✓
A change or shift	In family response/ expectations	✓	·	·	·	✓	✓	·	✓	✓	✓	✓
	Communication	✓	✓	✓	✓	✓	✓	✓	✓	·	·	✓
	Feelings about the situation	·	·	✓	·	·	·	✓	✓	✓	✓	·
	Relationships to services	✓	✓	✓	·	·	✓	✓	·	·	·	·
	Within the family	✓	·	✓	·	✓	✓	✓	✓	✓	✓	✓
Clinician attributes		✓	✓	✓	·	✓	✓	✓	✓	✓	✓	✓
Coping	Skills	·	·	·	·	✓	✓	✓	✓	✓	✓	·
	Family support	✓	✓	·	·	·	·	·	·	·	·	✓
	Independence	·	·	·	·	·	✓	·	·	·	✓	·
Challenges	Emotional	✓	✓	✓	✓	·	·	·	·	✓	·	✓
	Logistic	✓	✓	·	✓	✓	·	·	·	✓	✓	·

Sharing

Ten out of eleven of the papers refer to sharing. *Sharing multiple perspectives* refers to shared understanding, sharing of ideas and shared contributions by all involved in the intervention (not just the individual experiencing psychosis). Hearing that there were multiple perspectives instead of just from an expert felt useful and helped with open and honest conversations, for example, around medication and experiences (Florence et al., 2021).

Family member: “There’s always multiple, like, ways to go about it, and different thoughts to make other people think about solutions, or ways to help the situation. And it doesn’t always just come from them [therapists], you know.” (Gidugu et al., 2021, p. 157)OD.

“There was an appreciation for the way in which the network meetings gave the younger siblings a voice”. (Buus & McCloughen, 2021, p. 312)OD.

The perspectives shared by clinicians was also reported to be helpful by six papers. In the OD studies this referred greatly to reflections shared as a part of the intervention. Different perspectives shared in psychoeducation groups and FI were also appreciated.

Family approaches were also places where *things that wouldn’t be shared elsewhere* were able to be shared. It felt beneficial that a space was created for the purpose of speaking about experiences in a therapeutic setting. Some interventions, like OD, also mean that the network may have to confront their own vulnerabilities, histories and concerns (Buus & McCloughen, 2021). It was a commonality for papers to mention that these conversations would not be happening at home. Byrne et al. (2020) explained that several young people had not discussed difficulties with family prior to the FAs.

“Inviting the family in was reported to allow the network to discuss issues that would not be possible otherwise” “This is the first time we [are] all sort of in a room together to talk about what’s going on” (Florence et al., 2021, p. 1775)OD.

It was suggested that emotive conversation would otherwise be avoided, families felt they were failing to listen and that FAs helped with “emotional containment” (Florence et al., 2021); Rapsey et al. (2016) refers to the space being used to speak about difficult things in a different environment to one that could often lead to shouting. Psychoeducation groups also allowed this, where family members reported being able to talk about their own experiences or pain for the first time.

Family member: “I don’t have to hide anymore” (Levy-Frank et al., 2012, p. 271)**PG**.

The studies often referred to *shared responsibility*. Families appreciated being involved and actively having an opportunity to contribute to recovery. Gidugu et al. (2021) described the whole family as ‘equal partners’ and said that everyone had a say. Problems and responsibilities were described as shared, with families interpreting the work themselves.

Family member: “It’s not a one-person effort” (Florence et al., 2021, p. 1774)**OD**.

Increased understanding

All eleven papers contribute to the construction of this theme. Subtheme *Knowledge and understanding of mental health* refers to positive family experiences of gaining knowledge about psychosis, diagnoses, medication, stigma, employment and warning signs of relapse. Subtheme, knowledge and understanding was not a present for the OD informed interventions.

Parent: “I learnt a lot about it [experiences of mental health] I didn’t know” (Stanbridge et al., 2003, p. 196)**FI**.

Gaining knowledge also led to some changes in family perceptions. Developing insight was thought to be helpful in recognising the need for familial support (Nilsen et al., 2014b). Education also led to *“less pain from parents”* whereby *“they managed to make the illness seem more harmless than [they] used to believe”* (Nilsen et al., 2014a, p. 63). Increased knowledge and understanding of psychosis also helped families understand that there are side

effects from medication, recovery time was longer than they anticipated and that there were symptoms they were less aware of such as negative symptoms.

Family member: "I didn't really realize it was something to do with being a negative symptom at the beginning, I just thought it was him being a pain" (Rapsey et al., 2016, p.518)FI.

As well as describing increased understanding of mental health, an *understanding of experiences* was another sub-theme. This was an opportunity to feel understood in a way that had not been possible previously.

In some instances, gaining knowledge from professionals was considered unhelpful if this was too late after the first experience of psychosis. Listening to the experiences of those who had experienced psychosis themselves was consequently important for families to gain knowledge about the 'symptoms'.

"Listening to real life stories [of the service users in the group] helped families to imagine, or in some way understand, how it really was to be psychotic" (Nilsen et al., 2014a, p. 64)PG.

Through sharing their experiences families were able to come to a shared understanding in a process that helped them make sense of what the family member who had experienced psychosis had gone through but also what other family members had experienced.

Family member describing the experience with their family: "Each of us would have come in originally with totally different perceptions of what the issues were and how we reacted to them in the past and we found that by sharing those experiences we realized we had differences and we had a much better common understanding at the end of it" (Rapsey et al. 2016, p. 518)FI.

Sharing of experiences and a new understanding also allowed improvement of communication, support, more tolerance and reflection on past interactions. The unique understanding that families could share also felt positive in their contribution to helping the healing process (Nilsen et al. 2014b)**PG**.

A change/ shift

All papers describe a change or shift occurring as part of the family experiences. A change/ shift *in family response and expectations* refers specifically to the changes within family members and not the SU. A change in attitude was referred to changes in views around medication (Buus & McCloughen, 2021) or in how they perceived the SU. This change in how the SU was perceived encouraged some family members to be more active in thinking about their impact on the SU as well as their expectations of the SU. Families reportedly adjusted or lowered expectations for their family members in how long the healing process may take (Nilsen et al., 2014b) which allowed them to be more tolerant (Levy-Frank et al., 2012), put less pressure on their family member (Nilsen et al., 2014a) and react in a more helpful way such as by not shouting or nagging (Jensen et al., 2021, Rapsey et al., 2016).

Regarding a father: “[he] took responsibility for being a crucial part of the family’s stress... he started to change his behaviour” (Buus & McCloughen, 2021, p. 312)**OD**.

Family member: “I didn’t have patience, and I would scream and shout which would make my relative worse and after I did this [CaFI], it opened my eyes and made me more tolerant.” (Jensen et al., 2021, p. 281)**FI**.

Family member: “If we knew what schizophrenia was, we would not have put so much pressure on [patient]” (Nilsen et al., 2014a, p. 64)**PG**.

A change or shift in *communication* was a common finding amongst the literature reviewed. Papers that utilised OD approaches noted that new ways of communicating in meetings translated to communication at home, for example, through exploring and accepting

multiple perspectives and allowing everyone to feel heard (Buus & McCloughen, 2021; Florence et al., 2021; Gidugu et al., 2021).

Family member: “It was about creating common language” (Florence et al., 2021, p. 1775)**OD.**

Families reported feeling more comfortable with opening up and talking generally and reported that the SU was more likely to share things with them following the intervention (Levy-Frank et al., 2012; Byrne et al., 2020; Jensen et al., 2021; Nilsen et al., 2014b; Norheim et al., 2015). Ways of discussing difficulties or problems had reportedly improved rather than avoiding situations that may make the home environment more stressful (Stanbridge et al., 2003; Nilsen et al., 2014b; Rapsey et al., 2016).

Family member: “Our communication skills improved and changed the climate within the family... We are able to talk together in a different sort of way.” (Nilsen et al., 2014b, p. 4)

PG.

A sub-theme of a change *in feelings about the situation* was also constructed which refers to the emotional changes experienced by families as a result of the intervention. Less fear and anxiety was reported by families. A parent described how talking about the experiences “helped overcome fear associated with this daunting new experience”.

Parent: “It kind of removed the intimidation factor... there was so much dialogue, and so much talking and... it kind of made the whole situation not so foreign” (Gidugu et al., 2021, p. 158)**OD.**

There was also a reported reduction in guilt, shame, pain and pressure within families.

Family member: “I am no longer ashamed.” (Levy-Frank et al., 2012, p. 272) **PG.**

A change/shift *in relationships* both *to services* and *within families* was also apparent. All three OD studies referred to a change in the relationship to services. The studies refer to traumatic experiences, help-seeking experiences and difficult experiences with

hospitalisations, police and A&E. Descriptions of these experiences with services included feeling “desperate” (Buus & McCloughen, 2021, p.311), having “forced treatments” (Florence et al., 2021, p.1776 & p.1777; Gidugu et al., 2021, p.157), not being listened to (Florence et al., 2021, p.1783), having no trust (Florence et al., 2021, p. 1776; Jensen et al., 2021, p.284), feeling dismissed and feeling uncared for (Gidugu et al., 2021, p.157). Although facilitators of the OD interventions “had to put considerable work into demonstrating their good intentions, and to promote safety within the collaborative relationships they offered” (Buus & McCloughen, 2021, p. 311), the findings demonstrate a positive change in relationship to services following the OD intervention. Florence et al. (2021), for example, describes experiences of “empowerment” and “agency” in comparison to forced medication and not feeling listened to.

Jensen et al. (2021) and Stanbridge et al. (2003) both looked at experiences of FI and also described changes in the relationship to services. Stanbridge et al. (2003) described families as lacking confidence in services, having had previous difficult experiences and thus apprehension about the intervention. Attitudes changed to feeling less alone and like there was improved communication with services. Jensen et al. (2021) acknowledged reported fear and mistrust of mental health services among African-Caribbean individuals; the culturally adapted family intervention reportedly took a few sessions to build trust but eventually encouraged improved communication and conversation with professionals.

“The therapy enabled him to ‘tell him [doctor] things I haven’t told him before’”.
(Jensen et al., 2021, p. 278)**FI.**

Shifts in the relationships **within families** illustrates improved relationships between the family members who attended. This included descriptions of relationships that felt more supportive, accepting of involvement, communicative and the home environment and atmosphere.

Family member: "I didn't know how else. That I could be involved a way where he'd accept my involvement... I think it kind of made our relationship stronger" (Gidugu et al., 2021, p. 158)**OD**.

Clinician attributes

This theme refers to the attributes of the clinicians/ facilitators who led the interventions. The OD interventions referred to clinicians feeling non-hierarchical. This referred to the involvement of the whole network, the "non-pathologising stance", shared decision making and the transparency from clinicians, particularly in the reflections. Clinicians were thus seen as trusted because their motivations were known. Decisions were made with "no secrecy" (Gidugu et al., 2021), and clients felt clinicians were supportive of their choices; this was in comparison to previous services used where decisions were often made without their say.

The findings expressed good relationships with clinicians/ facilitators of psychoeducation groups, describing them as supportive and able to create safe spaces for the intervention. (Nilsen et al., 2014a; Nilsen et al., 2014b; Norheim et al., 2015). Levy-Frank (2012) also researched a psychoeducational group alongside a therapeutic alliance group. They referred to qualities of the therapists as empathetic and encouraging.

Family member: "She listened to me and supported me" (Levy-Frank et al., 2012, p. 274)**PG**.

The FI interventions additionally referred to therapist qualities such as trust, connection, non-judgmental, being knowledgeable, being friendly, patience, interested, containing and reflective.

Mother: "I felt very much understood. That was very overwhelming in a way, having come from a place where we weren't understanding each other at home, to have two people who were empathic there for me and for our son." (Stanbridge et al., 2003, p. 190)**FI**.

Coping

Learning new ways to cope through the intervention or through others was reported. *Skills* was a subtheme present in FI interventions and some psychoeducation groups but was not present in the OD studies. This included skills that helped with sleep, managing conflict, reacting to stress and coping with symptoms. Problem solving models and modules were reportedly helpful for families. Families also reported that acceptance was also a helpful way to improve coping (Nilsen et al., 2014b; Rapsey et al., 2016; Jensen et al., 2021).

Family member: “The problem-solving model made us able to solve our daily hassles by small interventions like sending a text message while my son was taking the train.” (Nilsen et al., 2014b, p. 4)**PG**.

Family members also refer to the intervention helping them cope with the difficulties experienced as a family; families reported that they were now more likely to share what happened with friends.

Parent: “I have finally learned different ways to cope with the overwhelming problems I am dealing with... I have learned to set clear boundaries for my son, so I can also live my life”. (Levy-Frank et al., 2012, p. 271)**PG**.

Family support refers to families providing ways of coping through their ability to support each other.

“It’s not a one person effort” (Florence et al., 2021, p. 1774)**OD**

Independence describes the family member learning to cope and manage more independently following the intervention.

“It has been a huge progress lately and I think it has something to do with time and her being able to handle her life in a more constructive manner.”(Nilsen et al., 2014b, p. 4)**PG**

Challenges

The theme challenges has two sub-themes: *Emotional* and *Logistic*. Studies referred to “interventions as difficult e.g. “emotionally taxing” (Buus & McCloughen, 2021, p. 311). Feelings felt in the intervention were described by some as uncomfortable, embarrassing, difficult, tense, scary, confronting, anxiety-provoking and distressing.

It was suggested that for some this was due to emotions that rose when sharing, for example, it felt shameful or scary to share experiences and it was unknown how this would be received (Buus & McCloughen, 2021; Byrne et al., 2020). It was also reportedly distressing and uncomfortable for families to hear some experiences and the impact that family members had had on each other (Florence et al., 2021; Byrne et al., 2020). In psychoeducation groups, anxiety was perhaps more related to having to share and talk in a group setting (Nilsen et al., 2014a). Norheim et al. (2015) described parents as not feeling challenged but that they were able to acknowledge the challenges and efforts the SU made.

Family member: “I feel like some of the open dialogues ended bad – like the first one, she stormed out in tears and they had to go find her” (Florence et al., 2021, p. 1779)**OD**

Parents: “They were a bit confronting” “I remember coming out feeling really drained”. (Buus & McCloughen, 2021, p. 311)**OD**

“It was probably one of the hardest things I’ve had to do sitting listening” (Byrne et al., 2020, p. 5)**FI**

Challenges were also *logistic* in nature. Approaches were described as “hard work” (Buus & McCloughen, 2021; Nilsen et al., 2014b). There was an increased amount of effort and time put into interventions which had to fit into busy lives (finding availability was a challenge). It was also challenging when family members refused to attend or commit (Florence et al., 2021; Jensen et al., 2021).

“Meetings were often squeezed in between competing family and work/education tasks and obligations”. (Buus & McCloughen, 2021, p. 311) **OD**.

Other challenges included a belief that it was difficult to participate in the interventions if the family member was currently struggling with symptoms. (Jensen et al., 2021; Nilsen et al., 2014b)

Family member: “The patients must be able to concentrate, take some medication, and not be too suspicious about others” (Nilsen et al., 2014b, p. 65) **PG**

Discussion

The aim of this synthesis was to draw out family experiences of various interventions for psychosis that include the family participating. Although the interventions were quite different in nature, there were themes that indicated similar kinds of positive experiences, regardless of the approach used. Themes also identified both emotional and logistical challenges in family interventions.

Throughout the synthesis, themes that indicated beneficial experiences of “increased understanding” within families and the increased “sharing” that occurred due to the family intervention were particularly striking. It seems as though families would not have shared experiences, different perspectives and developed as much of an understanding otherwise. It was also suggested that difficulties with communication would have remained prominent. The ability for family approaches to lead to positive change was apparent. The theme “clinician attributes” also adds to the established understanding of the importance of therapeutic relationships within psychological interventions (Martin, Garske & Davis, 2000).

A notable difference within the findings was that the sub-theme “increased knowledge and understanding of mental health” did not apply to the OD studies. This is key to how the families’ experienced interventions. OD approaches fundamentally step away from professionals being the expert and providing information about diagnoses and symptoms. In FI

and psychoeducation groups, the family experiences very much centered around understanding and learning about “symptoms” and an “illness” that their family member has been labelled with and consequently, how this was thought about and managed had a medical approach at the core.

Subtheme “skills” was also not present in OD approaches as well as one FI and one PG study. A professional that teaches skills takes a position of power and expertise- for example in making decisions about skills they see as helpful. In contrast, systemic approaches focus on changing the system rather than people. In OD, families are not seen as an object of treatment but as partners in the recovery process and they are empowered to come to their own understandings (Seikkula & Olson, 2003). Results in this review indicated that “a change or shift” can still occur for SUs, even when new “skills” are not directly taught (e.g. in improved communication or with relationship to services).

The dialogical nature of OD approaches means that experiences centered around a joint understanding and language that was not medical or knowing in nature when considering distress. How the problem was characterised was thus different.

OD approaches thus can be seen as consistent with social constructionist understandings which highlight the significance of language in acquiring meaning and emphasis on there being different perspectives and realities (Yerby, 1995). Systemic thinking in family approaches also focusses on family patterns and production of shared meaning for change to occur (Dallos & Draper, 2010). Family management is another approach taken with working with “psychosis” where a ‘disease model’ and focus on coping strategies and psychoeducation is taken. FI can perhaps be seen to use both family management and systemic family therapy techniques (Allen et al., 2013; Burbach, 1996).

Strengths and limitations

The systematic approach used to extract data, critically appraise the research and then synthesise the findings enhances the robustness of the findings (Thomas & Harden, 2008). There are very few qualitative studies on familial experiences of psychosocial interventions for psychosis, with most research focussing on quantitative outcomes or medication as interventions. This study therefore adds to the richness of understanding experiences through the individuals' own words.

A limitation of the review is that papers were varying in the type of intervention carried out and in which country, which meant that the interventions and service provision was different amongst studies. The modified CASP tool checklist does not require an appraisal of the demographic information provided. The studies, however, were lacking in diversity of participants with some studies not mentioning ethnicity at all (Buus & McCloughen, 2021; Florence et al., 2021; Levy-Frank et al., 2012; Stanbridge et al., 2003) and others acknowledging that their research was limited to all white participants (Gidugu et al., 2021; Rapsey et al., 2016). The studies in this review therefore lack transferability to wider populations. The research also recruited and interviewed families who completed interventions. Families who did not feel positively about the interventions were therefore not focussed on and future research may benefit from exploring the negative experiences. Additionally, there is a paucity of studies that explore experiences of each approach.

Clinical implications

The findings overall indicate that families are appreciative of being involved within services and benefit from interventions that include them. It is also suggested that interventions that include families lead to a decrease in distress outside of the sessions.

In all OD studies and two FI interventions, the intervention reportedly led to a change in the relationship to services, where families learnt to trust and access services that they had

previously had difficulties with. This suggests that including a family in interventions earlier on, may help individuals to access support and services. The transparency of the clinicians in OD interventions played a large part in gaining trust and in shifting power dynamics, and therefore interventions could think about ways to increase transparency and relationship to services. This could have implications to the uptake and engagement with FAs. A systematic review in the UK illustrated difficulties with implementing family interventions with estimated 0-53% families having the intervention (Ince, Haddock & Tai, 2016). Differing cultural beliefs can lead to families seeking help elsewhere (Conner et al, 2016). Approaches, such as OD, that allow for a network to share their own understandings and create their own meaning could help engagement with family approaches in UK services, specifically amongst families with beliefs that differ from the biomedical approaches which can be contested as mentioned previously. Favouring the wisdom of the family or network, transparency and communication, improving relationship to services, not labelling individuals with diagnoses and “illness” and empowering individuals as opposed to teaching knowledge and skills could be applicable when engaging families in other mental health services irrespective of the diagnosis usually given to the SU.

The specific intervention that families participate in can shape the lens by which the family view the individual’s difficulties (for example, if a family comes to their own understanding of experiences or whether a family learns about ‘symptoms’ and diagnoses). This could thus, impact, how a system makes sense of and views an individual.

Future research

Further research into family experiences of psychosocial interventions to increase diversity and ascertain whether these approaches are generalisable to different cultures is important.

As discussed, family approaches use elements of different models practically in services. As previously stated, FI is something that is used in UK services per NICE

guidelines. OD approaches are emerging. Future research could look at family experiences of approaches that implement elements of OD practically in the UK as this has not been explored. Research that explores elements that are important to families can help inform FA and different ways to support families within the NHS.

Conclusion

Bringing these papers together demonstrates the value that families place on being included in interventions during a time where their family member is experiencing severe mental distress in which there is increased understanding and communication, changes in responses, relationships and increased abilities to cope. There is room for further exploration of the experiences in families, particularly in the UK where there can be a difficulty in practically involving families in services.

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**Section B: Family experiences of an open dialogue
informed intervention in the NHS**

Word count: 7619 (**8371**)

SALOMONS

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Abstract

Background: Open Dialogue (OD) provides an approach to work with a system around an individual experiencing distress and managing crises. Clinicians are a part of the network and with service users and family members viewed as partners in the process. There is growing evidence for the effectiveness of OD as an intervention and it has been incorporated into services in varying ways. The present study aimed to explore family experiences of listening meetings which are an OD informed approach that has been adopted in an NHS Early Intervention for Psychosis Service. This can aid in gaining further understanding into experiences of the different ways OD is being practically implemented into already existing NHS services and ways to include a system as a network. **Method:** Seven family members were interviewed and results were analysed using Interpretative Phenomenological Analysis. Questions explored family experiences of listening meetings, any changes in family relationships and any changes in how family members relate to supporting the service user. **Analysis:** Four Group Experiential Themes were developed: 'As a family as a whole', Talking and listening that otherwise wouldn't happen, Making sense together, Relationship to help. **Discussion:** Participants reported a positive experience of the intervention: OD informed listening meetings allowed an impacted system to become involved in support, led to changes in relationships, encouraged communication, helped create a shared understanding of experiences and encouraged access to further support. Only one participant had any involvement with mental health services previously and reported a negative experience; they were less favourable towards the intervention. Future research could explore experiences of participants who have had experiences of services previously. Adapted OD informed approaches were described as useful in already formed NHS services.

Keywords: Psychosis, Family interventions, open dialogue

Family experiences of an open dialogue informed intervention in the NHS

Introduction

Involvement of families and carers

Inclusion of families and carers in mental health services is considered an essential aspect of good practice by statutory bodies (e.g. CQC 2017). More than 60% individuals in the UK return to family homes after an inpatient admission for a first episode of major mental illness (Barrowclough, 2003) and family involvement is considered important with recommendations of a minimum of 10 family intervention sessions after a psychosis diagnosis (NICE, 2014). Research has suggested that family interventions decrease recurrences of severe difficulties (Bird et al., 2010) but implementation of family interventions within services is poor (Haddock et al., 2010). Carers more generally have often reported feeling marginalised and excluded by care providers (Cree et al., 2015; Giacco et al., 2017).

The Triangle of Care approach (Carer's Trust, 2010), pioneered by carers in the UK, has been extended to cover all mental health services with encouragement of information sharing and collaboration in assessment, treatment and planning. Carers may be vital in aiding with support when professionals are not there and in noticing subtle changes and early warning signs of increased distress (Worthington et al., 2013). According to the cognitive model of caregiving (Kuipers et al., 2010), the appraisals of carers regarding the overall situation, difficulties of the service user (SU), and resources may vitally influence outcomes for all.

Open Dialogue

An Open Dialogue (OD) approach to mental health includes family, carers and other social network members as well as professionals as a consistent network from the beginning with all treatment taking place in the presence of the SU's support system in network meetings. OD is a way of structuring mental health services as well as a therapeutic intervention (Seikkula et al., 2003). OD originated in Finland and has drawn on a number of theoretical models,

including systemic family therapy, dialogical theory, psychodynamic principles and social constructionism. OD shares similarities with family crisis therapy where relational characteristics of the network are explored as opposed to locating problems within an individual (Freeman et al., 2019; Langsley et al., 1968).

Open dialogue network meetings focus on listening, putting words to experiences and meanings being made through creation of a joint language. Hope, empowerment and support through a network is aimed to be achieved through dialogical communication which allows for SUs and families to be at the core of the process as opposed to an expert-led symptom focussed, and diagnosis led approach. Themes for dialogue are not planned in advance; professionals follow words and language rather than an attempt to find explanations behind behaviour (Seikkula et al., 2003). There is a fundamental focus on ensuring transparency in communication, with decisions being made openly and all perspectives being heard which helps with the typical power discrepancy between professionals and SUs in mental health services (Seikkula et al., 2001; Tribe et al., 2019). Professionals are a part of the network and openly share responses and reflections of their experience of the meeting. OD is highlighted by the Council of Europe's compendium of good practices proposed to remove coercive elements in mental health settings as a matter of human rights (Council of Europe, 2021). Seven principles of OD, as described by Seikkula (2003), are highlighted in Table 1.

Table 1

The principles of open dialogue (Seikkula et al., 2003)

Seven Principles of Open Dialogue and description	
Organisational principles	
Immediate help	First Meetings will take place within 24 hours, all participate from the outset, the service user attends and shares dialogue/ stories at their most intense period of distress.
Social network perspective	Service users, families and other key members of the network (friends, professionals, agencies) are invited from the start to mobilise support, discussions are had

	around who could help and be invited, conversations about care take place in the network meetings collaboratively (including conversations amongst clinicians).
Flexibility and mobility	The response is need-adapted to fit to changing needs of the service user and network, the place for meeting is jointly decided, therapeutic methods that meet the needs of each case are utilised and agency to non clinical members of the network is encouraged in decision making.
Responsibility	The team takes charge of the whole process, all issues, thoughts, decisions and plans are openly discussed between the team within the network meetings.
Psychological continuity	Members involved in the first meeting will remain involved which could include the same network throughout inpatient and community settings. At least two clinicians will be a part of the meetings, additional members may join if this is necessary and other therapies can take place between meetings.
Principles of practice	
Tolerance of uncertainty	Premature plans and treatment plans are avoided, uncertainty is tolerated, dialogue takes place first. Building of a safe environment helps with this. Meetings can take place daily for the first 10-12 days to support this if required and then as often as the network wishes. Tolerance of uncertainty can be seen as an active attitude among the therapists who aim for a joint treatment process with the network and ensuring that decisions are not made as a reaction to events.
Dialogism and polyphony	Emphasis in generating dialogue not in promoting change in the service user or the family. New words and joint language is formed for experiences which do not have words or language. Listening to what people say is fundamental and new understandings are formed. There is multiplicity of accepted voices. No preformed objectives are discussed to allow for building of dialogue.

The evidence base and research in the UK

There is an encouraging emerging evidence base for OD as a treatment approach for individuals with experiences of psychosis. Research shows a decrease in use of medication and hospital duration after two years with 86% returning to full-time employment/ education at a

five year follow up (Seikkula et al. 2003; Seikkula et al. 2006). Bergstrom et al. (2018) found decreased duration in hospital, disability allowance and medication after 19 years.

A pilot study of OD in the United States interviewed SUs and their families and reported a theme of processing experiences and developing understanding within a family. This was found to decrease fear within the system and increase support to the client, which reportedly promoted communication and strengthened the support system. Families also reported exploring multiple perspectives in order for everyone to feel heard (Gidugu et al., 2021).

In the UK, Razzaque and Wood (2015) gathered perspectives of staff and SU attendees of an OD conference, which demonstrated agreement of potential usefulness of OD principles and for a framework for delivery in NHS mental health services. The study suggested that there are supportive attitudes to this approach but that there will also be expected challenges in implementation in NHS services. It was suggested that further research is needed to explore feasibility and provide a wider evidence base within the UK.

More recently, Wates et al. (2022) looked at practitioner experiences of OD training in the UK; participants believed the training transformed their practice positively in feeling deeper connections to clients and colleagues as well as feeling empowered to challenge poor practice in the workplace.

Another study explored staff and SU views of a modified OD approach whilst staff were halfway through training in OD in a UK service and found positive attitudes amongst staff, and SUs expressed feeling listened to and understood. Some SUs reported finding reflective conversation a little strange and one SU reported some distress (Tribe et al., 2019). There is a gap for exploration of family experiences of OD approaches in the UK.

The ODDESSI clinical trial (Open Dialogue Development and Evaluation of a Social Network Intervention for Severe Mental Illness) began in 2017 and is an on-going large

randomised controlled trial across different sites in the UK. It is funded by the National Institute of Health Research to consider the value of OD and potential implementation across the UK.

With a promising and developing evidence base, some services have built new teams to deliver OD and some services have incorporated aspects of the OD approach into their existing practices (Freeman et al., 2019).

Listening Meetings

Listening meetings have been developed, which are described by Hawkes and Reed (2015) as ‘early contact family meetings’ taking place within Early Intervention Services (EIS). These meetings utilise OD and systemic principles of engaging the network of a SU and working collaboratively from the first contact and were introduced to pre-existing services. Listening meetings are limited in number (approximately three sessions) and thus are a modified OD approach (Table 2 specified key aspects of meetings). In a London Early Intervention service, three 90 minute listening meetings are offered to a SU and their family/ social network.

Table 2

Principles of Open Dialogue that are specified as key within the three Listening Meetings offered.

<p>Aspects identified by Hawkes & Reed (2015) when considering Listening Meetings</p>	<ul style="list-style-type: none"> • For family meetings to be offered routinely at the first contact with services so that a collaborative ethos is created from the out-set • For meetings to be facilitated by staff from the clinical team, so that family work is not viewed as a specialist, ‘bolt on’ service that only a small number of people are referred to.
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<p>Characteristics of Listening Meetings that were identified from the work of Seikkula, & Arnkil, (2014) in conserving service characteristics for Open Dialogue.</p>	<ul style="list-style-type: none"> • Including the social network; A service user’s personal network (which may include people important to the SU, family or not) are invited to Listening Meetings to mobilise support for the SU and family. “They typically become important partners in the treatment process throughout” (Olson, Seikkula & Ziedonis, 2014, p9). • Dialogic Practice The conversations taking place in these meetings can be described as using ‘Dialogic Practice’ which refers to the form of therapeutic conversation within the family meeting. It is based on interactions where each participant feels heard and responded to and there is an emphasis on listening and responding to establish a conversational culture with multiple, separate, and equally valid “voices”, or points of view co-existing. Conversational culture is promoted by the team members to respect and hear all voices. • Adapting to Needs Needs are identified early on. Treatment is adapted to respond to changing family needs and circumstances.
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Rationale for the study

OD approaches have implications for services in managing crises, responding to severe mental distress and in providing a way to work with multiple people in a system as a network. As evidence continues to suggest the effectiveness of OD as an intervention, it is necessary to gain further understanding into experiences of the different ways in which OD is being implemented practically into services.

This study contributes to the question of how OD informed practice may contribute to any perceived change for SUs and their families in the UK and what is important about their experiences. Illumination of this process from the participants’ perspectives could inform family inclusive practice within services. Family and carer experiences of listening meetings

are important when considering the value of such approaches that include the social network, dialogic principles and adapting to the needs of a family, within the constraints of an otherwise largely unchanged (and still diagnosis-led) NHS context.

The present study aimed to gain an in depth understanding of the experiences of family members who have attended OD informed listening meetings. The focus was on family perspectives as this had yet to be a focus of exploration in OD research within UK services.

Aims and Research questions

The following research questions were explored:

1. What are the family members' experiences of listening meetings?
2. How (if at all) did participants feel the listening meetings contributed to any change in family relationships?
3. How (if at all) did participants feel listening meetings impacted how family members view their relationship to supporting the service user?

This project is grounded in certain NHS Values, including 'Working Together for Patients' and 'Everyone counts' due to the consideration of valuing both SUs and carers and the adaptations to needs which is fundamental to this approach. This also encourages a compassionate way of working because the approach ensures that each person's experience is considered, heard and thought about. Improving lives and enhancing positive outcomes are also considered because it is contributing to research in an area which could help develop recommendations to improve wellbeing and experiences of an NHS service and potentially reduce need for further input (e.g. medication or inpatient admissions). Commitment to quality of care is made because the aim is to ensure that the best care and patient experience is being considered.

Method

Design

This study used a qualitative design to allow an explorative in-depth approach. Individual semi-structured interviews took place with seven participants and an interpretative phenomenological analysis (IPA; Smith et al., 2009) was utilised to explore family experiences of OD informed listening meetings in the NHS, an emerging area of research.

IPA aids in an idiographic analysis of human experience and how people, in a context, make sense of their life experiences individually. There is a focus on personal meaning and sense making; considering content, the use of language and affect. This approach therefore fitted with the aims of the study in understanding experiences, where the meaning made within meetings is fundamental, but also fits with an OD approach where language helps to co-construct meaning (Seikkula, Alakare & Aaltonen, 2001). There is a recognised 'double hermeneutic' aspect of IPA where the researcher interprets participant interpretations of their experiences (Smith et al., 2009).

Expert by Experience Involvement

This research was discussed with an expert by experience (EBE) who agreed to support the research at various stages. This individual had lived experience of having a family member access early intervention services and attending OD informed listening meetings; they worked as a carer advisor within the service following this. They discussed potential research aims and questions and helped with the creation of the interview schedule through adapting questions for a fuller and richer exploration of experience. Sadly, they passed away unexpectedly during this research project, which cut short their involvement.

Recruitment

Participants were purposively sampled from a London NHS Early Intervention Service for Psychosis. Family members who had attended listening meetings were asked if they would

be interested to participate by care-coordinators or the listening meeting facilitators when having contact or a meeting with the team. The name and phone numbers of potential participants who agreed to listening meeting research were emailed to the lead researcher who spoke to potential participants on the phone. Participants were told that the researcher was looking to interview family members about their experiences of listening meetings and an online interview was scheduled if they were interested. Participants were also offered payment for participation. Participants were emailed an information sheet (Appendix C) and a consent form (Appendix D). Nine participants verbally agreed to take part in the research. Two people agreed and did not end up taking part after the conversation with the researcher. One said that they forgot the listening meetings and one didn't respond to communication following an initial phone call. Details of those who did not participate were deleted.

Inclusion criteria

Participants all met the following inclusion criteria:

- Adult family member/ carer
- Their family member met criteria to be accepted for the Early Intervention Service (named as having had an experience of psychosis).
- Family members had attended at least two of three listening meetings in the last two years.

During the initial phone call, it was suggested that participants should not participate in the study if they believed that talking about their experiences of services and the experiences of their family member may cause them distress. No one believed this would be the case and participants appeared enthusiastic to participate.

Participants

Small sample sizes are recommended for IPA studies due to the qualitative nature of research (Smith et al., 2009). Seven participants were recruited to the study; this was a decision based on the richness of data gathered which allowed for detailed analysis and fit within

recommendations for doctoral research (Smith et al., 2009). Participants recruited were family members of SUs. All participants reported that they had attended all three listening meetings and the time passed since their meetings was varied (one participant had finished the day previously but some time had passed for others); this was not specifically documented due to participant difficulties with remembering this detail. The family members consented to participate so only their demographic information and not those of the family member who accessed early interventions services were collected. Table 3 shows participant demographic information alongside pseudonyms given.

Table 3

Participant Demographic Information.

Pseudonym	Relative	Ethnicity
Hannah	Mother	Black African
Michelle	Mother	White British
Celine	Mother	Black African
Andrea	Sister	Black African
Esther	Wife	Black African
Jen	Daughter	White British
Lee	Father	White British

All participants came from different families.

Interviews

Data were collected through semi-structured interviews. An interview schedule was created to encourage the researcher to think about specific areas during the interview and potential follow up questions if the participant was less conversational (Appendix E). Questions explored family experiences of listening meetings, any changes in relationships and how families related to supporting the SU following the meetings. Interviews took place over

Microsoft teams which is a platform that many of them had used within the EIS. They were recorded via Dictaphone and this was transcribed verbatim.

Ethical Considerations

Approval was granted for the research proposal by the University (Appendix F). Approval was then also given by the NHS research ethics committee (Appendix G) and access of research approval was given by the specific trust in order to recruit from the service.

Informed consent was gained from participants to participate, to be recorded and to use quotations anonymously in the results. It was verbally acknowledged that the topic may relate to distressing or emotive experiences. Participants were told that they had the right to withdraw consent at any time (other than once transcription had taken place as it would not be identifiable) and that they did not have to answer any questions they did not wish to. As the interview related to the family experiences, the researcher was careful not to push for additional information specific to the family member who had accessed EIS and respected the information the family members chose to share. It was identified that conversations could be had with care coordinators if any participants became distressed but this was not the case. No risk issues arose during interviews. Interviews were audio-recorded, uploaded into a password protected folder and then deleted from the Dictaphone. Audio recordings were deleted once interviews were transcribed.

Procedure

Once a participant expressed interest in participating on the phone, an interview was arranged to take place on Microsoft Teams. Participants were sent an information sheet and consent forms to sign. Participants were able to ask questions at the meeting before consenting if they wished to. The researcher allowed up to an hour for the conversation to take place. Interviews ranged from twenty-five to fifty-five minutes long depending on detail participants

wished to share/ could remember. All participants said they were enthusiastic to participate and no distress was reported.

Data Analysis

The analysis was guided using recommendations by Smith et al. (2022). The researcher transcribed interviews and then read the transcripts multiple times to ensure familiarity. Exploratory notes were made which included descriptive, linguistic and analytical comments (See example coded transcript, Appendix H). Experiential statements were made by grouping exploratory notes by patterns and connections.

The transcript and experiential statements were then looked at to generate ‘Personal Experiential Themes’ (PETs) for each participant (Example, Appendix I). PETs were used to recognise patterns and encapsulate family members’ experiences through Group Experiential Themes (GETs) alongside sub-themes (example of formation in Appendix J).

Quality Assurance

The researcher took part in a bracketing interview (Appendix K) (Roulston, 2010) with a fellow trainee clinical psychologist colleague who was not involved with this research to identify and consider experiences, beliefs and preconceptions held by the researcher before analysis (Rolls & Relf, 2006). A reflective diary was kept throughout the research to provide additional space for reflexivity (Appendix L). Assumptions were thus held in mind and emotional responses and assumptions were documented on paper throughout. This information was included when adding diary entries and to be discussed in supervision. Personal reflections and preunderstandings were added in a different colour when coding (and acknowledged as part of the coding process, consistent with Smith et al., 2009) which was also discussed with a supervisor. Independent audit of the coding took place by a supervisor.

Reflexivity statement

I am a trainee clinical psychologist and find myself aligned to a social constructionist epistemology in relation to understanding mental distress. At the beginning of my career I was trained in hearing voices groups by the Hearing Voices Movement, where I first reflected on the meaningful and/ or understandable nature of voice hearing and the importance of considering social, cultural and political contexts surrounding unusual experiences. I have worked in an early intervention for psychosis team and have facilitated family interventions for psychosis but not used OD approaches clinically. I am aware of the diagnostic language used and explanation of symptoms surrounding access to services in the NHS. My supervisors and myself are enthusiastic by the idea of OD being rolled out in the UK. Conversations about this took place with the internal supervisor, who acknowledged the need to interrogate her own assumptions while viewing transcripts and coding.

Results

Findings were organised into 4 GETs and 10 sub-themes (Table 4)

Table 4

Group Experiential Theme	Sub-Themes
“As a family as a whole”	Inclusion impacting role Improved relationships
Talking and listening that otherwise wouldn’t happen	New talking and listening Meetings dampened the energy- emotions previously prevented talking and listening
Making sense together	Valuing voices to new perspectives “In their presence”- kind of enlightening

Relationship to help	A place that creates safety to speak and listen
	A bridge to accessing help
	Empowered voices
	Scratching the surface

“As a family, as a whole”

This theme described the relational nature of distress that occurred in individuals whereby the system was impacted but also involved with support. Families described the impact on themselves as exhausting and shared worries about how to manage themselves throughout. Lee described his son’s mental distress as “*an exhausting and many faceted beast*”. This description of distress suggests it as something with many differing features; uncertain and harmful even, communicating the significant impact on him and his family. Due to this impact and the role that participants had in supporting their family members, participants felt like it was fundamental to be included “*we thought about us as a family as a whole.*” (Michelle). This impacted how they related as a family also.

Inclusion impacting role

All participants had a role with supporting their family member. All but one described having a central role in reaching out for support for their family member in the first instance of their distress. They therefore felt it was crucial that they had a role within the services being offered to their family member and in participating in sessions.

“I have been, I think the main driver of getting the help and getting into the places and things like that.” (Jen)

“I was happy to be involved, I was fully involved, participated throughout all sessions and it helped me and my son to this day”. (Hannah)

Only Michelle had previous experience of accessing mental health services (CAMHS for her daughters). On the whole, she reported being unhappy with services including this one, but there were parts she was pleased with. One of those elements was being included via the listening meetings in the EIS whereas in CAMHS services this was limited. During the intervention, Michelle felt like this team considered the family.

“At CAMHS I had little feedback. They only tell you something if it is serious. And what professionals are on board. Whereas [this team] were sort of for the family and that connection.” “It did feel nice [to be involved] but it just wasn’t helpful enough.” (Michelle).

Participants, including Michelle explained that listening meetings helped them think about the role that they have with supporting their family member and increased their confidence in doing so. There was a feeling that families were going to work together to support the individual, that individuals felt that they could now do more and ‘step forward’ in their role. “[we thought about] *what we as a family can do together*”(Michelle).

Hannah described meetings as helping her to gain understanding in stepping forward into a role of support *“Initially I didn’t know how to play a role, I didn’t understand how to care for the person and the role to play to be able to support. That listening section helped me to play a role and understand better how to help him”*(Hannah).

One participant (Jen) described a role change in now being able to play less of a role and stepping back in supporting her father. She expressed feeling like she had been too involved with the care of her father *“no one in the world knows what I was going through”*. Jen was relieved when her father was accepted to the EIS and during the meetings; she felt as though she could have less of a role whilst a network of people around her father could step forward into a role of support.

“I took a big step back which I needed to by that point... she [my sister] stepped up and it allowed me to step back, but not just because these meetings allowed her to step up but

like because there was a group of people that was also there and everyone who had come from the family side was aware of what we were talking about”.

Improved Relationships

Five participants (Hannah, Michelle, Celine, Andrea, Esther) all suggested that meetings aided a positive change in relationships such as with bringing them closer together or relating better since the meetings. Esther’s husband moved out of the home following a described change in presentation and violence towards her. She thought the meetings helped with starting to rebuild relationships within the family.

“It started building up the relationship again with the kids, with me. The listening meeting started that” (Esther)

Jen did not report an improved relationship as she felt like their relationship had never been a good one. Throughout the interview she described an emotional journey when navigating their relationship: from worry to fear and isolation, anger and frustration and now pity. This feeling of pity towards him seemed like a new way of relating to her father.

“You can’t be angry at someone you pity” (Jen)

Jen hadn’t wanted to feel concerned or responsible for someone whom she had always had a difficult relationship with and thought that her past anger and frustration was driven by the weight of obligatory responsibility without knowing how to help her struggling father.

“It was a huge weight lifted. I think until that point it was very much like fear driven anger and annoyance.” (Jen)

Lee was the only participant who had just completed the meetings (the day before) and therefore his family were earlier into the process of support from the EIS. This might explain why, unlike other participants, he did not report positive change in the relationship, but like others reported that the relationships had changed due to the large and continued impact that trying to support his son was having on him and his wife.

Talking and Listening That Otherwise Wouldn't Happen

All participants referred to talking and listening that would not have happened if it wasn't for the listening meetings. This is related to there being a 'third party' involved. Professionals, as a part of the network, facilitated a space to talk and listen whilst providing mediation of sorts which encouraged talking that didn't feel so direct. Things were therefore confronted that previously were not and a lot of conversation that was dreaded turned out to be helpful.

New talking and listening

Many participants shared that they were not communicating much at all with their family members generally but a lack of talking and listening was exacerbated by confusion or frustration regarding the presentation of their family member following their experience of severe mental distress. Lee and Hannah both explained that the listening meetings seemed to encourage talking and listening, including dialogue that, at first, may have seemed unusual to family members.

"We became like where we don't talk. When he sees me he walk away(...) [the meetings helped with] not taking him as if, you know, what is he talking about? Taking him serious and listening when he is talking"(Hannah).

"It's allowing people to actually say things they wouldn't normally say, to the point that we got to the third meeting where [son] was saying things, not necessarily that seemed relevant, but that he hadn't been able to say before because they were quite out there, because he felt it was a forum where he could say what he wanted".(Lee).

Here, it seems as though Lee and Hannah are describing the sharing of unusual experiences, which became possible through dialogue which was accepted and taken seriously which was reflected by the serious tone in which they spoke about this.

Esther explained her understanding of the difference between her culture (in Africa) and the culture in the UK. She believed that keeping things to yourself is normal in the UK, whereas the network around a person in a listening meeting was similar to how people in her culture support one another.

“[In my culture] you cannot be low mood when you have everybody around. It’s not like that here. If you have a problem or something troubling here, there’s hardly anyone you can talk to about it. You keep it to yourself. He was born and brought up here so that is what he’s used to, keeping it to himself” (Esther)

Families believed that they were able to talk about things in listening meetings that otherwise would not have been said and thus hear things they may not have otherwise heard. Esther continued to explain why this space that encouraged talking felt important:

“Generally my spouse is someone that doesn’t really speak a lot. In that meeting I heard certain things that I’ve never heard in my twelve years of marriage. That was really impressive”

Conversation that was avoided previously was brought up in the listening meetings; both Celine and Jen both said that things had been *“brushed under the carpet”*, a metaphor which perhaps suggests an attempt at hiding the mess of the past. Participants felt like this really facilitated positive communication within families. Meetings were set up in a way where talking would occur whilst the rest of the network *“had to listen”* (Andrea) in that space.

Meetings dampened the energy- emotions previously prevented talking and listening

Families told a story of emotions previously getting in the way of talking and listening. Participants described how meetings facilitated *“being able to listen before reacting”* (Celine) which helped *“think before I speak”* (Andrea).

Participants found that they had previously been unable to effectively talk to each other because emotive responses impacted on the ability to listen but they were able to do this within meetings and continue outside of meetings.

“[In the meetings] he was communicating and I listened because before I would get angry. What are you talking? He too easily got angry and we would not listen. But that helped us now calm down, listen and understand and helped us have that relationship as mother and son.” (Hannah)

Similarly to other participants, Lee described being able to confront rather than avoid in the meetings and that the intensity of the emotions were lowered due to the nature of the listening meetings and the professionals present.

“I can see why you do it with other people because it deflects, dampens a little bit of the energy, shall we say” (Lee).

These quotations from participants describe tense atmospheres and emotion (or “energy”). Lee recognised the significance of the meetings in “dampening” this.

Several participants highlighted that fear and anxiety preventing talking. Participants were scared of saying the wrong thing or of a “*blame game*”(Jen) if they were to talk about things upfront. Celine thought that the listening meetings helped her family to overcome those concerns and described this as helping their ability to talk and listen to each other.

“It’s not like if we speak to each other about things we’re gonna feel ‘Oh am I gonna upset that person?’ because we got over that barrier through those meetings”(Celine).

Making sense together

Developing an understanding through talking and listening was described by participants as helpful. Everyone’s voice was heard and experiences and perspectives were shared which allowed families to make sense and understand. One participant (Michelle) did not like the aspect of the meeting that encouraged understanding; she felt this was too soon,

the process was too pushy and she wanted the team to provide solutions and support in what seemed like a more practical way.

“In crisis she still had to go to the meetings, whereas it should have waited until she was in the right space. It should have been support to help her through what she’s going through. It ain’t good to be pushy like that. Wanting to know why my daughter was doing these things. It wasn’t helpful trying to find out why things were happening.” “How to talk rather than why and understanding was better”.(Michelle).

Michelle’s unhappiness was conveyed by how she felt the meetings “should” have been; throughout the interview. Michelle appeared frustrated and it seemed as though she felt like sharing information in meetings was intrusive. Michelle, did however, believe that her family had developed a new understanding of *“how to communicate. What not to say and when to say things”*.

Valuing voices to new perspectives

Participants described how every voice was valued and the different perspectives they heard in these meeting led to increased understanding.

Most participants described how the facilitators made sure that every voice was heard. Jen, described every voice as being valued which appeared to be embedded into the process of the meetings.

“Every, single, person, who came, like, contributed, and I never felt like I couldn’t talk. And sometimes, you know, if I hadn’t spoken, they’d ask me directly, like, well, what do you [emphasis] think because you haven’t really said much. Which was nice.” (Jen)

Jen made an emphasis on the first three words and the word ‘you’ which suggests she valued all contributions and also felt valued.

Sharing perspectives and experiences was integral to increased understanding of experiences and making meaning of what had happened. Hannah, Jen and Lee all spoke about

sharing being reciprocal; they were able to hear the perspective of their family member but it also felt important to them that they were able to share their experiences, perspectives and needs.

“I was able to listen to him and that helped me to understand. What he needs, what he wants, what’s going on. And he also listened to me. What I need.” (Hannah)

Hannah said this whilst lifting her arms up in celebration, really demonstrating the importance she placed on the meetings ensuring that both voices were heard which led to joint understanding, suggesting that this felt like a big achievement. For Andrea, understanding her sister’s experience was fundamental to her making sense of what they were all going through and how she felt about the situation; she believed that a diagnosis was not necessary or integral to understanding.

“We all got to share our perspective... it’s actually helped me understand a bit more about what’s going on with her and just be a bit more understanding and a bit more patient I guess as well... I know more now than I did know then” “Even her just expressing what she’s experienced, I think even without the diagnosis, maybe would have given me more of an understanding as well”(Andrea).

Hannah, described the process of changing her perspective on her son’s behaviour through hearing his voice and perspective.

“I was just like, what is wrong with this guy? Why are you behaving like this? I didn’t understand. I was thinking he’s being laid back, he’s lazy, didn’t want to do anything... Now I am, wow, this is really what my son was going through”.

This change suggests a new connection to her son’s experience, Hannah portrayed frustration and confusion initially which seemed to calm in her new understanding.

Esther shared that she had developed understanding of a different cultural way of thinking about mental health which allowed her to think about how she reacts to her husband's difficulties.

"Where I'm coming from these kind of things are not common. We don't have things like depression, we have this better way of coping with it. You know, it's different. So I've never really seen anything like this before. So I got knowledge from the meetings that actually changed my perspective on about how I react to certain things and understand things differently"(Esther).

Lee described the significance of his daughter attending a meeting. He found it helpful taking a step back from his daily battle and considering her view of her brother.

"Obviously we're seeing him on a day to day basis. And so, you know, her view of it was just how confused and alone he seemed to be, and it was really important for me to hear because I have to deal with it almost like a battle... aggressive, volatile, controlling... it was interesting to see her perspective, how vulnerable [son] came over"(Lee). Here we see how the different perspective means that he could see his son in a different way.

"In their presence"- kind of enlightening

Five participants spoke about the presence of a reflective team, the process of the team reflecting back what they have heard or understood and the way that reflections helped with understanding e.g. in allowing things that have already been said to truly be heard which was *"Interesting. Kind of enlightening"* (Andrea).

Participants depicted reflections as allowing them to feel understood and listened to. Lee suggested a sincerity to the listening, where notes are not taken, making reflections powerful.

“No one writes anything down which is interesting... I think people like to feel listened to. And so when people reflect back on things that have been said, I think that’s quite powerful.”(Lee)

The presence of a reflective team reportedly aided with participants who were struggling to listen, taking things personally or who were misunderstanding and reacting emotionally when trying to communicate. Andrea shared that she felt like her sister had previously struggled to listen to the thoughts of others but was able to really listen to the professionals’ thoughts because they did not come across as taking sides, were not emotionally valanced about the conversation and simply reflected on what they had heard.

“Someone there who isn’t related to us and doesn’t have any sort of biases was there to explain clearly what was being said without all the emotion of it and she was able to take that on board” (Andrea).

Families also reported that the reflections made them really think about what they were saying in the meetings which led to them being thoughtful in their communication, thinking about the words used and wondering what will be brought up.

“[the reflective team feedback] made you focus. In yesterday’s meeting, I was thinking, well, I’m not gonna use the word ‘turbulent’ again, cause that got picked up last time, so I thought I’m not saying those things today” (Lee)

Relationship To Help

This theme illustrates the relationship to help in this process. This includes the experience of how participants found professionals, their experiences of accessing services, their new confidence and belief that they can use their voice if in need of support, but also the uncertainty they have been left with regarding further support.

A place that creates safety to speak and listen

Participants described feeling a sense of safety from their family member being accepted to the EIS. Jen described being included in the communication from services which helped with feeling less alone.

“We had these names and we had these people who were calling and they were looking into like how he was feeling and things like that, it's like, oh, it's not all on us like it's... there are other people who can help”(Jen)

Listening meetings were described as feeling safe, comforting and non-judgmental which consequently helped talking and relationships. This was referred to when describing the environment created and also perceived manner of the therapists. For Esther the environment felt comfortable and relaxed

“we're just jesting actually like friends or family sitting down to talk. I know one talk leads to another. Another talk leads to another, you know.” Esther said this with a large smile on her face as she shared the similarity of a network meeting to the way her family communicate in Africa, suggesting a sense of safety and warmth within the process of creating dialogue that really helped her to engage.

Lee felt like the environment was safe, professionals being present helped and that there was trust amongst the network.

“So you feel, so if I break it down, you feel safe, there's trust, you're with professionals it feels controlled and contained.”(Lee)

A bridge to accessing help

Five out of seven participants felt like their family had access to support following listening meetings. Being involved in the meetings gave families information about services but also encouraged individuals to access support. Jen explained that although her father hasn't been keen to participate in individual therapy, he has been accessing the employment support service and had attended some virtual psychosis support groups. She also said that

family that previously were not keen to engage have been open to any other involvement. Hannah expressed that the carer's support group was integral to her life at the moment and made her feel more comfortable to access support. Andrea explained how she also was now open to accessing further support. The listening meetings thus appeared to make accessing services such as support groups and family interventions more likely.

"It helped with joining other things, The meetings helped with being involved with other meetings, it's a bit more comfortable. we're currently doing now a few sessions with the family(...) and like referrals to any carers groups or further information that can actually give you more support and understanding, yeah it did help".(Andrea)

Lee, who was earlier into the journey, explained that he has had to find private therapy for his son because of the NHS waiting list but said that he felt so positively about his experiences and would happily access any further support that becomes available. As with previous themes, Michelle's experience represents a negative experience within the NHS: she said that she felt she was receiving no support and wasn't keen on the EIS or the care coordinator.

Empowered voices

Participants also reported that since attending the listening meetings they would now feel able and more confident to ask for support and also when speaking to professionals.

Both Celine and Andrea spoke about having a better understanding of their family member's experiences and now feeling empowered to seek support and speak to others about it. This was due to increased understanding, confidence, their role of being involved in the meetings and knowing that support was out there.

"You sort of feel a bit more confident in how to deal with what's going on, I can ask questions... I'm not scared to talk to those who I need to talk to about it because I feel I have

enough knowledge and understanding through those meetings to be able to share my thoughts and understanding with others, to continue to help and support him”(Celine)

“If I do want to speak to someone, I guess I’ll know what to say or not now. We’ll know what to mention”.(Andrea).

Listening meetings, thus empowered families to have a voice.

Scratching the surface

Participants described positive experiences of being involved in their family member’s care, the improved communication and understanding but expressed some concern with the limited number of meetings offered and a wish for more with some uncertainty at what is next. Jen spoke about feeling less aware of what was happening next and fed back that she wished there were more meetings further into the process to stay involved. She believed there was a lot they were unable to cover in three sessions.

“I just think that actually if I were to do it again, I would probably have a list myself of the things that I would want to cover”.(Jen)

Both Lee and Celine also indicated that there was more they wished to uncover together as a network.

“And you only get three hits, so you know. I think we were only just starting to scratch away at the surface on the third one.”(Lee)

“Even if I had another meeting like this session, I think I would have a lot more questions to ask”(Celine)

Lee also expressed that as well as three meetings not feeling enough, they were too spread out as significant and impactful events were happening in between the meetings.

Discussion

This research aimed to explore family experiences of OD informed listening meetings which took place in an early intervention service within the NHS. There was also a focus on any changes in family relationships and the relationship to supporting the SU. Participants overall spoke positively about listening meetings. **“As a family as a whole”** described the relational nature of distress; this theme captured the systemic understanding that individuals are a part of a wider family network where there are relationships, roles, responsibilities and ways to communicate (Bowen, 1993). The value of the sessions was therefore inherent. An individual’s distress impacts the surrounding systems and the systems respond by impacting the individual in a reciprocal way known as circular causality (Hall, 1981; Kellely & Lyons, 2019). This theme described the impact on families, a change that occurred in their involvement in supporting their family member and the change in relationships between family members.

Meetings opened up **Talking and listening that otherwise wouldn’t happen**. Things that were previously avoided, never confronted or just did not have a space to be spoken about could be brought up in the listening meetings. Meetings also allowed for talking and listening to happen, where emotions were said to previously have got in the way of this happening effectively. This is fundamental to dialogism as an outline for communication amongst the network. Seikkula and Olsen (2003) explain the social constructionist perspective of psychosis as extreme and frightening alienation from communication where very difficult experiences do not have words and people are without a voice. This theme highlights that this approach was found to encourage dialogue and language where it often does not occur. The approach also encouraged **Making sense together**. This was a theme that reflects an important part of OD approaches which is developing an understanding through sharing of language. In dialogical practice, individuals are supposed to feel heard and reach

shared understanding in voicing experiences (Olson, Seikkula & Ziedonis, 2014). This was something that was still reported as taking place in just three meetings. Having third party involvement (a reflective team) as a part of the network meeting seemed to really aid in talking and enabling understanding. Seikkula (2002) hypothesised that having team members who have not been a part of the emotional reaction to the crisis helps families with uncertainty, listening carefully to the dialogue and responding in ways that assist with the dialogue.

Relationship to help captures the journey of participants in their relationship to services. Although expressing positive experiences, participants wished there were more sessions. Participants reported feeling relieved, safe, contained and not alone. A good experience of listening meetings meant that they were open to or accessing other services offered and also felt empowered to reach out for support now; this fits with a key aim for OD approaches which is to empower the network to understand and confront difficulties (Seikkula et al., 2003). However, one participant with negative experiences of health services indicated that they were unhappy with support and were not accessing the other services. This participant, unlike other participants, had prior experience in health services as a carer and reported minimal communication and involvement from those services.

OD is a different approach to the typically offered community mental health services and full integration of OD at an organisational and therapeutic level would require a fundamental change in epistemological positions in mental health settings, existing structures, values and power dynamics which could prove challenging and be met with resistance (Cotes et al., 2023; Von Peter et al., 2023; Tribe et al, 2019). Although adaptation of approaches will be necessary for practical implementation, this raises a question regarding the decisions made around the crucial elements of OD which are included and the aspects which are unable to take place within the NHS. A profound finding of this study is that core aspects identified as

fundamental to OD were reported and valued in the experiences of families who had experienced an adapted shorter OD informed approach (just three sessions) within an already established NHS framework which is largely informed by the medical model.

Strengths and Limitations

The loss of the expert by experience was sad and a loss to the study. It was a real strength and privilege to have them involved in the beginning when considering the questions to ask in the interview and for the researcher to get an understanding of the meetings and service.

There was a diverse group of relatives (parents, siblings, partners, daughters) but perhaps lacked diversity with only one male and participants identifying as either Black African or White British. Participants were recruited from one NHS site; sample size and qualitative design means that results may be considered not generalisable. Smith (2017), however, believed that qualitative research can be generalisable to application of theory or models in to understanding (analytic generalisability). Information was shared about participants and context, without it being too identifying of individuals, as this helps in thinking about transferability to people with similar experiences and in similar contexts.

Participants described a significant impact and change in their lives and a limitation may have been a potential influence of demand characteristics; participants may not have been completely truthful in fear of losing out on the care they reportedly were so relieved to have been offered despite my detached role and confidentiality being discussed.

Clinical Implications

This study aligns with the Triangle of care key standards set out by the Carer's Trust's (2013) guide to services; trusts in the NHS are working towards this to promote collaboration with carers through mental health services.

Participants in this study reported feeling contained, safe and comfortable, but there was one participant who was not as positive in sharing their experience. This participant had experience of mental health services previously and reported that although the meetings were helpful with thinking about ways to talk and bringing their family together, they felt unhappy with facilitators trying to encourage sharing of understanding and experiences. Previous research suggests that a strength of OD is the increase in trust to services (e.g. Freeman et al., 2019). It could be hypothesised that three OD informed meetings felt helpful for those without prior experience of services but that three meetings may not be enough to rebuild trust or is less beneficial to those who perhaps already lack trust in services.

This study adds to the emerging research of OD-derived approaches, illustrating that OD informed interventions can be embedded into pre-existing NHS services and also work well within an EIS. It adds to the importance of dialogical practice and the use of this within systemic theory and therapies. Experiences from family members illustrated the value family members placed on their involvement.

With vast changes required to implement OD as discussed previously, it would be imperative for staff to align with this way of working and a socially constructed understanding of mental distress which would require “buy in”, extensive training and costs. There could be a risk of this being undermined by more conventional interventions without a sufficient critical mass of support, especially at management and leadership level.

Future Research

This research highlighted the significance of family involvement when a family member has experienced substantial mental distress. Future research could explore clinician experiences of integrating OD within existing NHS services. Future research may also explore the relationship to help further; experiences of SUs and families who have had previous involvement with mental health services and, in particular, previous negative

experiences of services. Research could investigate any increase or decrease in family engagement within the service as a result of OD informed approaches; this may be helpful due to the limited uptake of family interventions in the UK (Haddock et al., 2010). Research that explores experiences subsequent to the three listening meetings may help to further understand the impact of listening meetings on the family's journey and involvement.

Conclusion

This study explored family experiences of OD informed network meetings known as listening meetings following an episode of severe mental distress experienced by their family member. Participants found listening meetings valuable and felt like it was important for them to be involved, specifically due to the impact of the mental distress on the system. Participants felt like listening meetings enabled them to feel supported and they thus felt more equipped to support their family members. Participants emphasised that listening meetings enabled talking and listening that had previously been difficult and that their voices were valued. They were able to make sense of the experiences of those in the network through increased understanding and appreciated the reflections from the team. Participants believed that meetings helped with the ability for the family to access support in the future, with a good experience of professionals and confidence to have discussions about their family member's distress. Participants, however, felt three meetings only scratched the surface. This study has implications for clinical practice, where it demonstrates the beneficial experience of an OD informed network approach and including the family and SU from the beginning of their journey with mental health services. Future research would benefit from exploring OD informed approaches and whether this is impacted by the family's relationship to help.

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Section C: Appendices

Appendix A *CASP GUIDE*

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Appendix B

Quality appraisal of identified studies using modified CASP checklist

First author	Buus & McCloughen (2021)	Byrne et al. (2020)	Florence et al. (2021)	Gidugu et al. (2021)	Jensen et al. (2021)	Levy-Frank et al. (2012)	Nilsen et al. (2014)a	Nilsen et al. (2014)b	Norheim et al. (2015)	Rapsey et al. (2016)	Stanbridge et al. (2003)
Aims clearly stated?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the research design justified?	P	Y	Y	P	Y	P	P	P	Y	Y	P
Appropriate sampling strategy and description of recruitment?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the data collection method described appropriately?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was researcher reflexivity addressed?	N	N	N	N	N	N	N	Y	P	Y	N
Have ethical issues been addressed and approved?	Y	P	P	N	Y	P	P	P	Y	P	Y
Was data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Has the value of research been considered?	Y	Y	Y	Y	Y	Y	P	P	P	Y	Y

Appendix C

Participant information sheet

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

www.canterbury.ac.uk/appliedpsychology

Information about the research

Exploring family experiences of open dialogue informed listening meetings

Hello. My name is Amber and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

Talk to others about the study if you wish.

(Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?

There is some research on service user experience of listening meetings but little on family member experiences. Involvement of family and carers is an essential aspect of good practice in mental health services.

Listening meetings have the aim of engaging the network of the service user and working collaboratively from the first contact.

This research is about exploring your experience of this approach. Illumination of this process from your perspectives could potentially inform family inclusive practice within services, and other services could learn from and adapt similar ways of working.

Why have I been invited?

I am reaching out to families or carers who have experienced listening meetings and am hoping to speak to 8-10 families.

Do I have to take part?

It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

I would meet with you to interview you on one occasion for approximately 45-90 minutes. This interview will be audio recorded. The research will last until approximately September 2023. To ensure confidentiality, you will be given a data number to identify your personal data (name and address) which only the researchers will have access to until interviews have taken place, after which this will be destroyed. Interview recordings will be stored on an encrypted and protected drive and will be destroyed once transcribed. Pseudonyms will be used when writing up the results and you will not be identifiable.

Expenses and payments

Whether we meet in person or online will depend on the current pandemic context and government guidelines. If we were to meet in person at a SLAM NHS trust building such as

[Removed for confidentiality] early intervention service, I can reimburse you a maximum of £10 for travel. There is also a payment of £10 for participation as a token of appreciation if you wish to accept this.

What will I be asked to do?

I will ask you about your experiences of the listening meetings and ask that you share as much information and detail as you feel comfortable with. As previously mentioned, this will be audio recorded. I predict that this interview will take approximately 45-90 minutes. We can have a short break in the middle if you wish.

What are the possible disadvantages and risks of taking part?

If you believe that talking about your experiences of the listening meetings may cause you significant distress, I would advise that you do not participate in the study.

What are the possible benefits of taking part?

Gaining an understanding of family and carer experiences of listening meetings will help further our understanding of the usefulness of this approach in the UK and NHS settings for individuals who have experienced psychosis. Research could potentially inform family inclusive practice within early intervention services and other services could learn from and adapt similar ways of working.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

Please see the university's privacy notice information sheet
<https://www.canterbury.ac.uk/university-solicitors-office/docs/research-privacy-notice.docx>

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don't want to carry on with the study?

If you decide to withdraw from the study all of your interview data can be destroyed if you wish.. You would need to contact me within one month of your interview, because after that time the interview data will be anonymised and incorporated into themes along with other data and it will be more difficult to identify and remove it.

What if there is a problem?

Any complaint or concern regarding your interactions or involvement in the study will be taken seriously and addressed (see section below on complaints).

Concerns and Complaints

If you have any questions please contact me a.iszatt352@canterbury.ac.uk.

If you have a concern about any aspect of this study, you should ask to speak to me and I

will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me, Amber, and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology fergal.jones@canterbury.ac.uk

Will information from or about me from taking part in the study be kept confidential?

Families/ carers who have participated in listening meetings will be sent this information regarding research. To ensure confidentiality, you will be given a data number to identify your personal data which only the researchers will have access to. Interview recordings will be stored on an encrypted and protected drive and will be erased once transcribed. Pseudonyms will be used when writing up the results and you will not be identifiable.

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else.

What will happen to the results of the research study?

There is an intention to publish the results from this study. You will not be identified in any report/ publication. Any quotes will be anonymised. A short summary of findings will be available to all participants on request by emailing me after. All participants will be offered the option to comment on the findings before they are finalised.

Who is sponsoring and funding the research?

Canterbury Christ Church University.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by [name of committee] NHS Research Ethics Committee.

Further information and contact details

If you would like to speak to me and find out more about the study or have questions about it answered, you can email me at: a.iszatt352@canterbury.ac.uk or leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me, Amber, and leave a contact number so that I can get back to you.

See above for information about who to contact if you have any concerns about this study.

Thank you for reading this information. Please contact me via the above if you are interested in taking part.

Appendix D

Consent form



Salomons Institute for Applied

Psychology

One Meadow Road, Tunbridge Wells, Kent TN1 2YG

IRAS Project number **309658**
 Version number: 4 Date: 21/05/22
 Participant Identification number for this study:

CONSENT FORM

Title of Project: Family and carer experiences of open dialogue informed listening meetings
 Name of Researcher: Amber Iszatt

Please initial box

1. I confirm that I have read and understand the information sheet dated.....
 (version.....) for the above study. I have had the opportunity to consider the
 information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any
 time without giving any reason

3. I understand that relevant data collected during the study may be looked at by the
 researcher, Amber Iszatt as well as lead supervisor, Sue Holttum. I give permission
 for these individuals to have access to my data.

4. I agree for the interview to be audio recorded on a Dictaphone.

5. I agree that anonymous quotes from my interview and other anonymous data may
 be used in published reports of the study findings

6. I would like to receive the study findings (meaning the researcher will
 keep my contact details for a longer period of time).

7. I agree to take part in the above study.

8. I would like to receive a summary of the study findings (*optional*)

*If I tick this box then I consent to my name and contact information being kept
 for a longer period of time to receive this summary.* yes

no

*Consent forms will be stored for a year at CCCU and then shredded. Any electronic copies will be stored in a secure university
 electronic drive for a year and then deleted. You will be asked if you want a copy of this form.*

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

Appendix E

Interview Schedule

Focus area	Example questions and probes
Introduction questions	<ul style="list-style-type: none"> -At what point of your contact with services did you have the listening meetings? -Did the service user attend any or all of the meetings? -Who was at the meeting? -How often did you have these meetings?
General about listening meetings	<ul style="list-style-type: none"> -What were your expectations before the meetings? -Tell me about your experience of the first listening meeting? -What do you remember about the meetings after the first listening meeting -What were the differences between other contact you have had with mental health services? -Were there any aspects of the meetings that you found to be positive or helpful? -Were there any aspects of the meetings that you found to be unhelpful?
<p>How the family relate to the difficulties experienced by the service user and relationships within family</p> <p>Going to ask about your experience of relationships in the family:</p>	<ul style="list-style-type: none"> -What were relationships like in the home before the psychosis? <i>Tell me more? What made it X.</i> -In the run up to the meetings, what were the family relationships like? -How do you feel your family relationships are since the meetings? <i>Changes, same?</i> -Did attending the meetings affect how you see the difficulties of your family member? <i>Any differences? Same?</i>
How the family view their relationship to supporting the service user	<ul style="list-style-type: none"> -How did you feel about your involvement in the meetings? -Has attending meetings affected how you see your role in supporting the service user at all? If so, could you say how?

Appendix F

University proposal approval

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Appendix G
NHS ethical approval

Appendix H

Jen's (participant 6) coded transcript

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Appendix I

Development of personal experiential themes for Jen

Example quotations have been removed from electronic copy

PET (N= 6)	Sub-theme (N=)	Experiential statement	
Things would not have been spoken about otherwise	Conversation previously avoided	<ul style="list-style-type: none"> •Talking felt difficult for the family •Jen thought conversations should have taken place but hadn't •Family pushes things aside instead of talking •Team prompted conversation that needed to be had •Helped talking take place that wouldn't have happened •Spoke about things in depth in meetings •Conversation about emotive things were had •Staff helped prompt important conversation when stuck •Previous fear that talking doing the wrong thing/ talking being unhelpful •helped have conversations that wouldn't have happened 	
	Emotions prevented conversation happening	<ul style="list-style-type: none"> • Initial apprehension to talk but this changed •Fearful to discuss certain things •Dreaded some conversation •Becoming agitated would prevent talking •Fear stopped talking •Emotional response that occurred at home did not happen in meetings •fear of blame 	
	Continued at home	<ul style="list-style-type: none"> •Struggled to continue conversation at home at first •Helped have conversations at home they wouldn't have/ weren't having 	
Family role	Family involvement	<ul style="list-style-type: none"> •Wish to stay involved 	

		<ul style="list-style-type: none"> •Jen had previously got him support for mental health •Role in getting support •Jen had to make decisions and seek out family to speak to about her parent •Jen wants to make sure he is ok and gets support •Didn't want to be involved because difficult relationship with father but felt she had to •Didn't know how to be involved but was expected to •Resentment/ frustration over involvement •Involved in thinking about future support •Continued involvement 	
	Change in role- able to step back/ forward	<ul style="list-style-type: none"> •Being accepted to a service meant Jen could step back •Jen was supported and not feeling alone •Encouraged other family to become more involved •Felt like no one knew what she was going through and she didn't know how to help •Able to step back and have less involvement •family confidence to help 	
	Emotion and wellbeing change due to role change	<ul style="list-style-type: none"> •Less angry after listening meetings •Family calmed down a lot •Fear had turned into anger •Frustration at not knowing how to help but feeling she had to •Started to feel pity instead of anger •Feeling supported meant that Jen felt less fear and less anger •Fear and anger at having to be responsible and act •relieving •really needed to step back, relief 	

		<ul style="list-style-type: none"> • Won't be able to cope if there is a relapse 	
Containing		<ul style="list-style-type: none"> • Expected it to not go well but it was good • Safe space • Therapist traits • There's a team to support • Comforting • Understood • Visible people who are there • Non blaming • Professionals equipped to help • not alone 	
Sharing	Sharing thoughts	<ul style="list-style-type: none"> • Sharing different opinions • Sharing perspectives on how family member is doing/ what being better means • Sharing past experiences • Shared perspectives • Hearing everyone's voice • Increased sharing with family 	
	Professionals sharing	<ul style="list-style-type: none"> • Reflective team shared their thoughts about what had been said • Thinking about reflective team thoughts • Reflections prompted conversation • Professionals sharing their ideas and plans for what is next with network- less in the dark? • Sharing of resources • Sharing knowledge when conflict over what was said/ agreed in team • Sharing of psychoeducation and support groups before meetings 	
Accessing support		<ul style="list-style-type: none"> • Support is there • Showed you can reach out to people • Hasn't accessed individual therapy • Open to accessing other support in service • Know about other support 	

		<ul style="list-style-type: none"> •Attended a group •Became visible that there are people who are there •Family want to know what services he is accessing 	
Wanted more input		<ul style="list-style-type: none"> •Not frequent enough to keep conversation going •Uncertainty about future input •Not enough sessions •Sessions later on in the process would be helpful also •Nervous there are no more •Could have used them better •Valued the space 	

Appendix J

GET development

Talking that otherwise wouldn't happen

- A space to address things and listen, Confronting/ no longer avoiding (past, things for first time, continuing at home)
- Emotions prevented talking

The process of understanding through dialogue

- sharing perspectives, sharing experiences, listening and talking
- reflective team

Family role/ relating/ impact

- Role or involvement
- impact on the family
- relationship

Containing and safe space

- boundaried, containing, safe
- the characteristics of the therapists? i.e. warm, comfortable

“It didn't scratch the surface”

- amount of time/ sessions
- accessing services

Appendix K

Pre-analysis bracketing interview

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Appendix L:

Abridged research diary

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Appendix M:

Feedback report for ethics panel

Background: Open Dialogue (OD) provides an approach to work with a system in a network to help with managing crises for individuals experiencing severe distress. There is growing evidence for the effectiveness of OD as an intervention and it has been incorporated into services in varying ways. The present study aimed to explore family experiences of listening meetings which are an OD informed approach that has been adopted in an NHS Early Intervention for Psychosis Service in order to gain further understanding into experiences of the different ways OD is being practically implemented into already existing NHS services and ways to include a system as a network.

Aim: The study aimed to explore family experiences of OD informed listening meetings in an EIS. The following research questions were explored:

1. What are the family members' experiences of listening meetings?
2. How (if at all) did participants feel the listening meetings contributed to any change in family relationships?
3. How (if at all) did listening meetings change how family members view their relationship to supporting the service user?

Method: This used a qualitative approach called interpretative phenomenological analysis (IPA) to explore family member's experiences of listening meetings. Seven family members were interviewed.

Outcomes: Four main themes were found across the data and 10 subthemes. These are illustrated in the table below.

Conclusions: A positive and useful experience of listening meetings were reported. Appreciation and usefulness of family and carer involvement was clear. Findings were consistent with existing key elements of open dialogue demonstrating an opportunity to incorporate adapted OD informed approaches in pre-existing NHS services. Experiences of systemic involvement and improvements in relationships, developing shared understandings, encouraging talking and listening, improved access to services and feelings of safety were reported. Participants felt like three sessions were not enough and were not frequent enough during this time of severe distress. One participant reported a positive experience in bringing the family together but expressed that they were unhappy overall with the service and mental health services in general. It could be hypothesised that three OD informed meetings felt helpful for those without prior experience of services but that three meetings may not be enough to rebuild trust or less beneficial to those who perhaps already lack trust in services.

Further exploration and understanding of the ways in which OD approaches are being incorporated into NHS services would be beneficial. Exploration of family experiences who have had previous involvement with mental health services will be useful.

Group Experiential Theme	Sub-Themes
“As a family as a whole”	<p data-bbox="810 394 1126 427">Inclusion impacting role</p> <p data-bbox="810 465 1107 501">Improved relationships</p>
Talking and listening that otherwise wouldn't happen	<p data-bbox="810 539 1142 573">New talking and listening</p> <p data-bbox="810 622 1353 696">Meetings dampened the energy- emotions previously prevented talking and listening</p>
Making sense together	<p data-bbox="810 719 1267 752">Valuing voices to new perspectives</p> <p data-bbox="810 790 1334 828">“In their presence”- kind of enlightening</p>
Relationship to help	<p data-bbox="810 869 1318 936">A place that creates safety to speak and listen</p> <p data-bbox="810 965 1150 999">A bridge to accessing help</p> <p data-bbox="810 1037 1054 1070">Empowered voices</p> <p data-bbox="810 1111 1094 1149">Scratching the surface</p>

Appendix N:

Feedback report for participants

Family experiences of listening meetings

Background: The present study aimed to explore family experiences of listening meetings. These meetings draw on an approach called Open Dialogue (OD), a way of working with people's social network.

Aim: The study aimed to explore family experiences of listening meetings. The following research questions were explored:

1. What are the family members' experiences of listening meetings?
2. How (if at all) did participants feel the listening meetings contributed to any change in family relationships?
3. How (if at all) did listening meetings change how family members view their relationship to supporting the service user?

Method: Seven family members were interviewed.

Results: Four main themes were found across the data and 10 subthemes. These are listed in the table below.

Conclusions: Participants reported a mainly positive and useful experience of listening meetings. Experiences of family involvement and improvements in relationships, developing shared understandings, encouraging talking and listening, improved access to services and feelings of safety were reported. Participants felt like three sessions were not enough and were not frequent enough. One participant reported a positive experience in bringing the family together but expressed that they were unhappy overall with the service and mental health services in general. It could be suggested that three OD informed meetings felt helpful for those without prior experience of services but that three meetings may not be enough to rebuild trust or may be less beneficial to those who have experienced services more negatively.

Further exploration and understanding of the ways in which OD approaches are being incorporated into NHS services would be beneficial. Exploration of family experiences who have had previous involvement with mental health services will be useful.

Group Experiential Theme	Sub-Themes
"As a family as a whole"	Inclusion impacting role Improved relationships
Talking and listening that otherwise wouldn't happen	New talking and listening

	Meetings dampened the energy- emotions previously prevented talking and listening
Making sense together	Valuing voices to new perspectives “In their presence”- kind of enlightening
Relationship to help	A place that creates safety to speak and listen A bridge to accessing help Empowered voices Scratching the surface

Appendix O:

Declaration of the end of study form

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Appendix P:

Journal information for publishing

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

About the Journal

Psychosis is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Psychosis accepts the following types of article: Research Articles, First Person Accounts, Brief Reports, Opinion Pieces, Letters to Editor and Book Reviews.

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Peer Review and Ethics

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