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PSYCHOSIS, FAMILIES, AND OPEN DIALOGUE

Section A: What is the experience of family members and significant others caring for a loved one experiencing First Episode Psychosis?

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Section B: The experience of attempting to create organisational change: An Interpretative Phenomenological Analysis of the experience of clinicians integrating Open Dialogue to NHS psychosis services

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Declaration

This has been removed from the electronic copy.

Acknowledgements

With thanks:

To the participants who gave their time and shared their experiences with me.

To my two supervisors, Sue and Jo, who showed unwavering kindness and support throughout this project, particularly during times of great difficulty.

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Finally, to my sweet brother, James, who we lost along the way. I know you would be proud.

Summary of Major Research Project

Section A: First Episode Psychosis can be distressing for both the individual and their loved ones and significant others. Literature indicates that family caregivers play an important role in providing care for their loved ones, however, the experience of caregiving can be challenging. Few attempts have been made to synthesise the qualitative literature within this area to understand the overall experience of caregiving. This qualitative literature review focused on the experience of caring for a loved one or significant other in a non-professional capacity during First Episode Psychosis. Five themes were identified: 'The positives of care', 'The future is uncertain', 'Shame and stigma', 'The emotional demands of care', and 'The practical demands of care'. Future research and clinical implications of this review are discussed, including suggestions for Early Intervention in Psychosis service provision.

Section B: Interest in the OD approach continues to develop across the world, and the UK is amongst the countries assessing the feasibility of integration. There is very little qualitative data that explores the experiences of clinicians attempting to integrate OD and bring about change towards adopting OD within the existing structures of NHS psychosis services. This area of research is yet to be explored, and, arguably, it is a particularly important time to begin. Seven clinicians from a variety of disciplines were interviewed and Interpretative Phenomenological Analysis (IPA) was used to analyse the data. A total of four Global Experiential Themes emerged: 'Recalibration journey', 'The redistribution of power', 'Anxiety and resistance to change', and 'Creating the change'. The findings and clinical implications are discussed in relation to existing literature.

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Section A

What is the experience of family members and significant others caring for a loved one with First Episode Psychosis? A systematic review and thematic synthesis of the qualitative literature

Word Count: 7,428

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Abstract

Background: There is an increasing movement to develop our understanding of the experiences of family members and significant others providing care for a loved one during First Episode Psychosis (FEP). The literature indicates that caregivers play an important role in good outcomes for their loved one, but the experience of caregiving can be distressing. Synthesising the literature within this area could potentially illuminate a deeper understanding of the caregiving experience, which could in turn inform research and clinical practice. **Method:** the literature was systemically searched and chosen in line with the inclusion criteria from several databases. A total of seven qualitative articles met the inclusion criteria and were included in this review. **Outcomes:** five themes emerged from the thematic synthesis that may represent the overall experience of caregiving. **Discussion:** clinical and research implications discussed.

What is the lived experience of family members and significant others caring for a loved one during first episode psychosis?

Terminology

Throughout this study the terms ‘psychosis’ and ‘FEP’ have been used. This is to communicate research findings within a common framework of understanding to the reader. The author recognises the limitations of this framework, such as non-medical and non-western explanatory models of understanding that may be discounted (Saravanan et al., 2008). For this reason, other medical language associated with psychosis (e.g. ‘symptoms’, ‘relapse’) have not been subscribed to.

Psychosis

Psychosis is a construct that is commonly conceptualised within a medical framework of understanding, which is particularly dominant within Western society. Within this context, psychosis is typically defined by the presence of ‘symptoms’ including seeing and hearing things others do not (‘hallucinations’), believing things that others do not (‘delusions’), a lack of motivation and speech, and withdrawal (‘negative symptoms’) (McGorry et al., 2008). Debate pertaining to the development of psychosis exists, although there is some agreement that psychosis may impact those with a bio-psycho-social ‘vulnerability’ (Garety et al., 2001; Zubin & Spring, 1977). This ‘bio-psycho-social’ understanding of psychosis implicates a range of complex and interacting factors including; childhood trauma (Read et al. 2014), adverse environments, illicit drug use, emotions, and cognitive processes such as attention, perception, and judgment (Garety et al., 2001).

The experience of the ‘positive symptoms’ of psychosis can be intensely distressing (Rodrigues & Anderson, 2017; Shaner & Eth, 1989;) and may understandably be appraised as a traumatic and ‘life shattering event’ by the individual (Birchwood et

al., 2003). The experience may be so terrifying it could precipitate the onset of post-traumatic stress disorder (PTSD) (Lundy, 1992; Morrison et al., 2003; Shaner & Eth, 1989; Shaw et al., 1997). It is also common for a period of depression to follow an episode of psychosis when the ‘positive symptoms’ begin to remit, and in some cases this period carries a high risk of suicidality (Birchwood et al., 2000; Birchwood et al., 2003).

Psychosis and family

The continuing shift from institutionalised mental health care to community-based mental health care across western society (Kuipers & Bebbington, 2004; Luderowski & Boden, 2020) has increasingly led to the responsibility of caring for those with mental health needs to fall to family members and significant others, who take up the role of ‘carer’ in a non-professional capacity (Eassom et al., 2014). A supportive family network and home environment during psychosis can lead to a more positive trajectory and improved quality of life for the individual experiencing psychosis (Sin et al., 2021), highlighting the critical role that families play throughout all stages of psychosis (Mui et al., 2019). However, supporting a loved one with psychosis may be burdensome (Alvarez-Jimenez et al., 2012), leading to significant distress (Barrowclough et al., 1996) and a range of painful emotions such as feeling anxious and low for the caregiver (Addington et al., 2005). The process may be effortful as family members attempt to understand their loved one’s unique experience that may, at times, feel impossible to make sense of (Luderowski & Boden, 2020).

The importance of the environment within the family home in relation to recurrence rates of psychosis has been thoroughly researched and the construct of ‘expressed emotion’ (EE) was developed in 1966 (Brown & Rutter, 1966; Heru, 2021).

EE refers to the emotional milieu within the family home and is characterised by critical comments, hostility, intrusiveness, inappropriate and inflexible strategies in dealing with difficulties, and emotional over-involvement of family members towards the individual with psychosis (Barrowclough & Hooley 2003; Heru, 2021). Research has highlighted the potential negative impact of high EE family environments (Stowkowy et al., 2012). Frequent recurrences of psychosis are common following FEP and one study estimates that 80% of individuals with FEP may experience a recurrence within the following five years (Alvarez-Jimenez et al., 2012), although this may be contested in the literature. Recurrence is more likely within high EE family environments compared to low EE family environments (Barrowclough & Hooley 2003; Heru, 2021), and research has shown that the relationship between EE and increased recurrence rates is maintained in any geographical location worldwide (Bebbington & Kuipers, 1994). Criticism from caregivers has been highlighted as a particularly significant factor in relation to increased recurrence rates (Alvarez-Jimenez et al., 2012) and unfortunately poor mental health on the part of family caregivers may render them less likely to provide quality care and more likely to act in a critical or hostile manner towards the individual being cared for (Sin et al., 2021). Although this literature is important to consider, it should be noted that EE could be experienced as blaming psychosis on family dysfunction, which may disregard the genuine challenge that caregivers face (Selick et al., 2017). Furthermore, in recent years more attention has been paid to the majorly important role that families play in supporting a loved one with psychosis (Selick et al., 2017). It is therefore essential to reduce the burden of psychosis on the individual and the family network.

Early Intervention in Psychosis Services

Research has highlighted the importance of intervening early on in psychosis, which can significantly impact the course and outcome (Doyle et al., 2014; Fusar Poli et al., 2017). In addition, living with a family member and the involvement of a family member in treatment may reduce the likelihood of disengagement from services (Conus et al., 2010; Doyle et al., 2014). As a result specialist Early Intervention in Psychosis services (EIPS) were introduced to the U.K. in 1999 (Neale & Kinnair, 2017) and provide specialist care for a period of three years following FEP. FEP refers to “an individual who presents at a clinical setting with psychosis and who has never previously presented at a clinical setting with psychosis” although it should be noted that this definition can vary across clinical and research settings.

The National Institute for Health and Care Excellence (NICE) guidelines recommend psychosocial intervention in the form of ‘family intervention’ (FI). FI is a core component of the broad-based treatment package offered to clients under the care of EIPS, aiming to reduce the burden and distress of psychosis for the individual and their family members (Fusar Poli et al., 2017; Miu et al., 2019; Edwards & McGorry, 2002; Neale & Kinnair, 2017) and reduce caregiver distress and high EE within the family environment (Barrowclough & Hooley, 2003). However, the rates of FI implementation within services and uptake from families remain low (Selick et al., 2017), which is a cause for concern as caregivers may be left without sufficient support.

Summary

It is evident from the research presented that the current structure of UK mental health services means that the role of providing care is likely to fall to family members and significant others. It is evident that the family play an important role in

supporting their loved during FEP and their involvement can have a positive impact in different ways, such as better outcomes and service engagement. However, the role of caregiver can sometimes be challenging and despite the aim of EIS to provide support to carers, implementation and take up of FI by families remain low.

To date, the literature within the field of psychosis is mostly quantitative (Mui et al., 2019) and qualitative research within this area has been limited, however, there is an increasing movement to understand how the client and their families experience psychosis for the first time (Noiriel et al., 2020). Synthesising the qualitative literature in relation to the overall experience of family members and significant others providing care for a loved one with FEP could elucidate different aspects of the caring role that hold important clinical and research implications.

To the author's knowledge, few researchers have attempted to assimilate the findings from qualitative studies exploring the experience of relatives in relation FEP, but one review did consider 'early' psychosis (which spanned up to a period five years after the onset of psychosis) (Mui et al., 2019). However, this study by Mui and colleagues (2019) did not focus specifically on FEP and excluded other key members of the network such as spouses and close friends that could be considered primary care givers.

Aim and rationale

It is hoped that by synthesising the qualitative literature a more detailed understanding of caring for a loved one with FEP may emerge. The aims of this study are:

1. What themes materialise from qualitative literature in relation to the experience of family members and significant others caring for a loved one during FEP?

2. To summarise the different parts of this experiences
3. To potentially inform future research and service provision within EIPS.

This review therefore endeavoured to answer the following research question: what is the overall experience of family members and significant others providing care in a non-professional capacity to a loved one with FEP?

Method

Literature search strategy

The following electronic databases were systemically searched: OVID, PsychInfo, PubMed, Medline, Web of Science, and Google Scholar. The search was conducted in November 2022. No lower limit to dates was applied in order to yield as many relevant papers as possible. Additionally, the reference lists of included papers were searched manually to search for any further relevant papers.

The following search terms were used: (Experience OR Qualitative OR Exploration OR Family experience OR Lived experience OR Family burden) AND (Carer OR Carer relative OR Family carer OR Family OR Families OR Loved one OR Caregiver OR Care giving OR Family care giver OR Primary care giver OR Relative OR sibling OR spouse OR family network) AND (first episode schizophrenia OR early psychosis OR first episode psychosis OR psychosis). Limits were placed on publication language to articles published in English that were accessible at the time of the search through the lead researcher's university account.

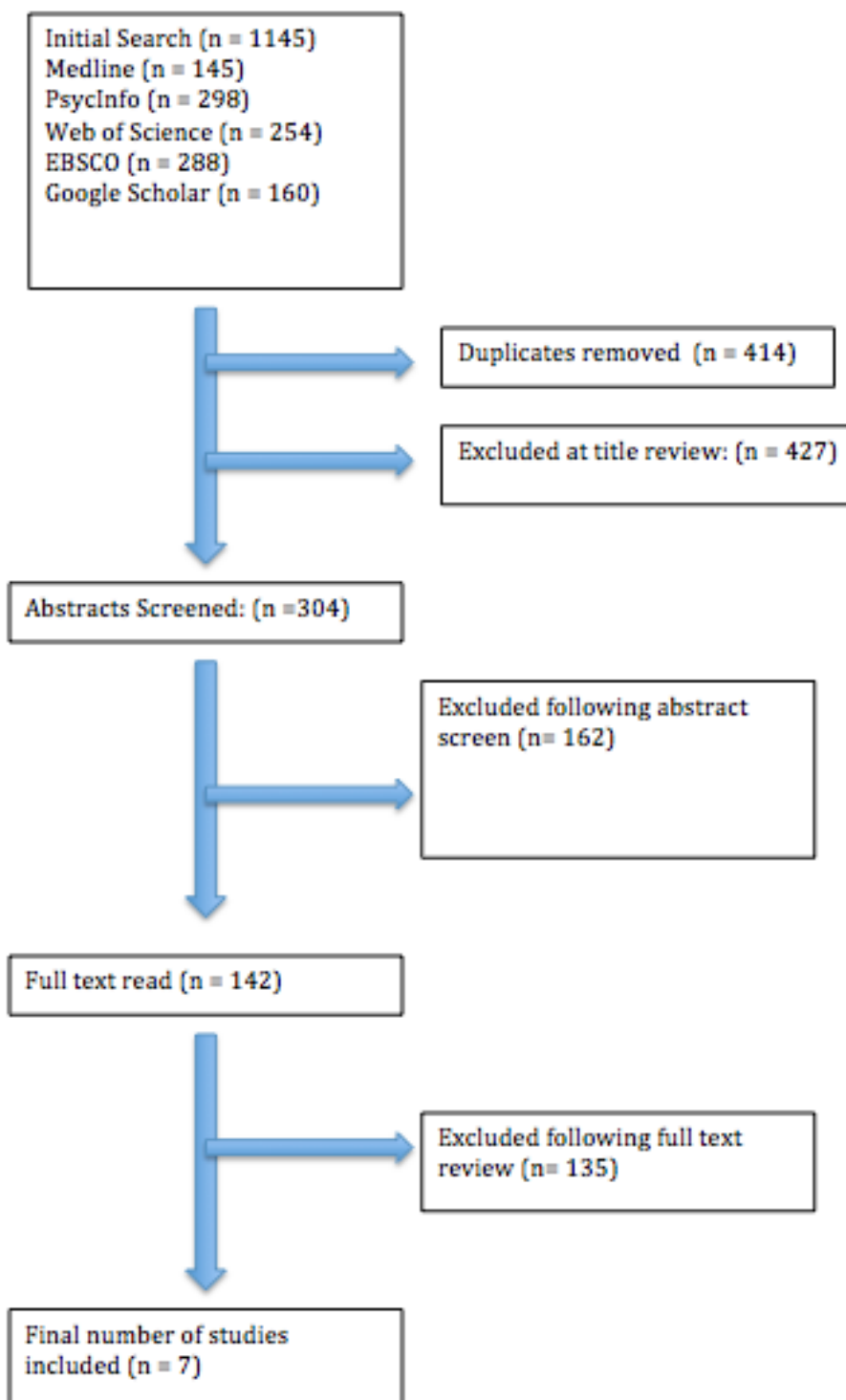
Inclusion criteria:

Papers in this review were required to meet the following criteria:

- Participants must be family members or significant others caring for a loved one with FEP
- Over 50% of the paper focused on the experience of care during FEP
- Qualitative papers

Research Selection

A total of 1,145 papers were returned from the initial search with a total of 414 duplicates that were subsequently removed. Several papers were not accessible with university permissions and so were excluded from the review. One potentially relevant paper on the experience of violence towards caregivers during FEP was returned but not accessible (Onwumere et al., 2019). One further relevant paper of note was a doctoral thesis, which was not included (Hamilton Wilson, 2012). Several papers were returned that explored family caregivers experiences of seeking help from mental health services. The majority papers were not included for a number of reasons. Firstly, the high number of papers on help seeking specifically could warrant a systematic review on this area of research alone. Due to the scope of this review in line with the parameters of a doctoral research project, it was decided to exclude these papers. Secondly, including these papers may have shifted the focus of this review from the overall experience of caregiving during FEP. One included paper (Sadath et al., 2014) is titled ‘caregiving and help seeking during FEP’. However, once the full text was reviewed it was evident that over half of the content detailed the broader experience of caregiving during FEP. The search process can be seen in the PRISMA flow diagram (figure 1).



Research Quality Assessment Method

The Critical Appraisal Skills Programme (CASP, 2018) checklist was employed to assess the quality of each study (Appendix x). CASP is a useful tool to assess the quality of qualitative literature. This provided the researcher with a baseline to compare and contrast the quality of papers against each other, and to take the quality into account when deliberating the results of this review.

Review

This review begins with a brief outline of the papers. Thematic Synthesis (Thomas & Harden, 2008) was used to generate themes from the included papers that reflected the overall experience of family members and significant others providing care during FEP. Thematic synthesis was chosen to provide a more meaningful and richer overview of the different aspects of the caring role and what this experience may be like for family caregivers, as opposed to simply describing the findings of papers which may not yield a rich result.

Thomas & Harden's thematic synthesis involves three stages: coding texts, developing descriptive themes, and developing analytic themes. In keeping with this structure, the findings of each included paper were 'coded' line by line to summarize the content codes (e.g., 'care is complex = some positives and some negatives', 'feeling burdened', 'conflicting emotions'). The initial codes were then reviewed for similarities and differences and grouped together. These groups were then given a new code that captured the broader meaning that began to emerge from their amalgamation. The final stage of the synthesis is developing analytic themes; "going beyond" the original content of paper is key (Thomas & Harden, 2008, p. 7).

The researcher inferred what the experience of caregiving may be like for family caregivers, based upon the grouped codes, that answered the research question of the review. Throughout this process the themes were discussed with supervisors, and themes were developed or changed accordingly as new meanings emerged. A total of five themes were derived from the seven included papers. The methodology of each paper is then reviewed. Finally, the research is discussed in relation to existing literature and theory, and clinical and research implications will be discussed.

Description of studies

This review will present the key findings from a total of seven papers. An overview of each paper can be seen below (table 2). All studies were qualitative.

Table 3: Summary of papers table

Study	Design	Sample	Data Collection	Analysis	Key Findings
Kumar et al. (2019)	Qualitative	<ul style="list-style-type: none"> • N = 30 caregivers of young adults (15-25 years) with FEP in a public hospital in India. • FEP defined as: schizophrenia, schizoaffective disorder, other nonorganic psychoses. • Duration of psychosis 3 months – 2 years. • In contact with services for 3 + months. 	Focus group discussions	Grounded theory	<ul style="list-style-type: none"> • Seven broad themes relating to first time caregiver experience and needs. • Wanting information about possible treatment. • Carers struggling to understand and needed information about FEP. • Pervasive worry and stress. • Uncertainty.
Lavis et al. (2015)	Qualitative	<ul style="list-style-type: none"> • Present qualitative findings from a larger project (super EDEN) between 2010-2015 across five UK NHS EIS. • Caregivers 	<ul style="list-style-type: none"> • In depth longitudinal interviews between 2011-2014. • Included caregivers 	Iterative thematic analysis	<ul style="list-style-type: none"> • Three broad themes emerged, summarised below: • Caregivers discussed what their role involves including

		nominated by loved one with FEP.	completed at least 1 interview by 2013.		maintaining normality and being vigilant.
					<ul style="list-style-type: none"> • How caregiving feels including rewarding and distressing. • Experience in relation to support from EIS.
McCann et al. (2011)	Qualitative	<ul style="list-style-type: none"> • 20 first time family caregivers to young adults with FEP. 	1 x 1 hour semi-structured interview.	IPA	<ul style="list-style-type: none"> • Six competing themes identified reflecting the carers experience of supporting family member with FEP: • Burdensome responsibility • Roller coaster and unpredictable experience • Feeling responsible for their illness • Coming to terms with the change • Becoming closer • Maintaining hope
Penny et al. (2009)	Qualitative	<ul style="list-style-type: none"> • Families receiving 	1 x semi structured	IPA	Three themes emerged

		<p>care from EIS, Birmingham UK.</p> <ul style="list-style-type: none"> • Participants identified as Pakistani or British Pakistani. • Living in UK between 10-35 years • 11 family caregivers for loved one with FEP 	interview		<p>from the data:</p> <ul style="list-style-type: none"> • A story of loss detailed sense of loss and change of hopes for the future and for their families future. • A social problem understood psychosis as a social issue • Divergent points on the path of change included spirituality as a way of coping.
Sadath et al. (2014)	Qualitative	<ul style="list-style-type: none"> • 11 family caregivers for a family member with FEP. 	1 x 90 minute semi-structured interview.	Content analysis	<p>Major themes:</p> <ul style="list-style-type: none"> • Help seeking and faith-healing practices • Explanatory model of illness • Illness management strategies • Financial burden • Perceived stress and stigma.
Sin et al. (2008)	Qualitative	<ul style="list-style-type: none"> • 10 sibling (aged 16-35 years old) 	1 x semi structured interview	Responsive-Reader method	<ul style="list-style-type: none"> • Emotional impact of care included

		<p>caregivers of family member with FEP.</p> <ul style="list-style-type: none"> • Under the care of UK EIS. 		(no formal qualitative analysis)	<p>shame, embarrassment, worry, and stress.</p> <ul style="list-style-type: none"> • Changed relationships within the family and siblings worrying about parent caregivers. • Siblings viewing role and supporting parent caregivers and providing normality.
Sin et al. (2012)	Qualitative	<ul style="list-style-type: none"> • 31 siblings caregivers (17-35 years old) of family member with FEP. • Family under the care of UK NHS EIS. 	1 x semi structured interview	Responsive-Reader method (no formal qualitative analysis)	<ul style="list-style-type: none"> • Siblings viewed their role in various ways including practical and emotional support. • Caregiving brought positives such as resilience and personal growth. • The experience of having a sibling with FEP is distressing.

Table 4: summary of themes

Theme	Papers included in theme	Example quote from research
The Positives of Care	Lavis et al., 2015; McCann et al., 2011; Sin et al. 2008; Sin et al., 2012	<i>“It has affected . . . [the family] but in a way, like, we’ve become a really, really close family as well. Very close, so, at the same time, it’s a good experience, in getting us all close”.</i> (Sin et al., 2012)
The Future Is Uncertain	Kumar et al., 2019; Lavis et al., 2015; McCann, Lubman & Clarke, 2011; Penny et al., 2009; Sadath et al., 2014; Sin, Moon & Harris, 2008	<i>“We are worried about our younger son. Will he also get this illness? Our elder son was well a few years ago. How will we know if our younger son gets the same illness?”.</i> (Kumar et al., 2019)
Shame and Stigma	McCann et al., 2011; Penny et al., 2009; Sadath et al. 2014; Sin et al. 2008; Sin et al., 2012;	<i>“Younger siblings under 16 years old, commonly reported feelings of embarrassment and behaviours such as keeping their brother’s or sister’s illness hidden from school and friends and not inviting people to their homes”</i> (Sin et al., 2012)
The Emotional Demands of Care	Kumar et al., 2019; Lavis et al., 2015; McCann et al., 2011; Penny et al., 2009; Sadath et al., 2014; Sin et al., 2008; Sin et al., 2012	<i>“We always think about our child’s illness! We constantly feel tense about it! We try to divert our mind but still we could not stop this worry”</i> (Kumar et al., 2019, p. 439)

The Practical Demands of Care	Kumar et al., 2019; Lavis et al., 2015; Penny et al., 2009; Sin et al., 2008; Sin et al., 2012; Sadath et al., 2014	<i>'Trying to remember her appointments, trying to help her cope with some of the everyday problems that she has to deal with, e.g. laundry and housework and just being at certain appointments at certain times'</i> (Mother of Leila, 24)
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The Positives of Care

This theme captures the positives that caregivers experienced, despite the emotional challenges the role may bring. A total of four out of seven papers contributed to this theme (Lavis et al., 2015; McCann et al., 2011; Sin et al. 2008; Sin et al., 2012). Sin et al. (2008) found that siblings reported meaningful personal growth and development due to assuming a caregiving role. This included becoming more sensitive and understanding towards others. For example, one sibling reportedly felt they had 'grown up quicker' and had learnt to 'open up' and become 'aware' of other people's feelings. This sense of personal growth was shared by the siblings in Sin et al. (2012), who reflected upon how they had become more understanding, sensitive, and considerate.

McCann, Lubman, & Clarke (2011) found that caregivers experienced strengthened bonds with their loved one. This was the case for caregivers that had existing strong relationships with their loved one, and caregivers that did not have a strong bond before FEP began. Despite the challenges of the caregiver role, there was indeed a sense of an enhanced bond between caregivers and recipients. Sibling carers in Sin et al. (2012) reported similar experiences, although in relation to cohesion within the family unit as a whole. For example, there was a sense that their family unit had become more resilient and able to deal with adversity. One sibling caregiver

reflected upon how FEP had been a ‘good experience’ because their family had subsequently become ‘really, really close’. There was a sense that caregiving felt rewarding for some of those interviewed in Lavis et al. (2015). The rewards were wide ranging and included enhanced bonds between themselves and their loved one, enjoying spending time with their loved one, and learning about themselves on a deeper level through the caring role.

The Future Is Uncertain

Another theme that emerged was the feeling of uncertainty in relation to the future for caregivers: both their own personal future and in relation to their families’ future. Six out of seven papers contributed to this theme (Kumar et al., 2019; Lavis et al., 2015; McCann, Lubman & Clarke, 2011; Penny et al., 2009; Sadath et al., 2014; Sin, Moon & Harris, 2008). One caregiver in McCann and colleagues (2011) described the unpredictable nature of caring for a loved one with FEP as a ‘rollercoaster’, which highlights the sense of uncertainty that the role is accompanied by. Periods of distress and relief would seemingly ebb and flow depending on how their loved one was managing with the psychosis.

Parent caregivers in Kumar et al. (2019) also appeared to be impacted by the fluctuating course of FEP and the uncertainty that accompanied it. Witnessing the sudden change from ‘well’ to ‘unwell’ in their child with FEP was understandably experienced as very distressing. This appeared to generate concerns that their other children may also develop psychosis, and this made the future feel unsettling.

For siblings in Sin, Moon & Harris (2008), uncertainty took a different form. Siblings reported altered perceptions related to their personal plans for the future, such as future relationships and having children of their own. This appeared to be mostly due to witnessing the distress that their sibling had been through as a result

of FEP. The distress felt so overwhelming that some siblings distanced themselves from the relationship as a coping mechanism because they could not 'deal with it'. It could be argued that this sense of wanting to remove oneself from the uncertainty that came with FEP stemmed from self-protection. This appeared to act as a catalyst for change in relation to future decisions, such as having children. For example, in an attempt to protect himself from the uncertainty of the future, one male sibling 'split up' with his partner because no longer wanted children.

Caregivers in Lavis and colleagues (2015) discussed a complex and continual process of adjustment as a result of the uncertainty that FEP seemingly brought. There was a sense of needing to take things slowly, and adopting a 'day by day' approach allowed carers to avoid thinking about the future and possible long-term ramifications of FEP. This 'day by day' style of coping with uncertainty appeared to be related to a complicated relationship with hope for the future.

This feeling was echoed by the caregivers in Penny and colleagues (2009) who recognized the importance of holding hope for their own and their relative's future, but this hope waxed and waned depending on their loved one's phase of psychosis (acute vs. recovery). For example, in the initial stages of FEP carers had hoped that their loved one would be 'fully recovered' within a few months. However, over time their expectations shifted from hoping for a full recovery to seeking smaller positive changes that felt reassuring. It could be argued that there is a reciprocal relationship between hope and uncertainty.

Caregivers in McCann et al. (2011) also spoke about the importance of holding hope as a caregiver in order to manage the uncertainty of the future. Hope was discussed as a multi-faceted concept, with three sub-types: 'hope in transition',

‘fostering hope in the young person’, and ‘developing hope as a caregiver’. Developing hope as a caregiver seemingly allowed caregivers to see beyond their current difficulties in relation to their caring role, and this mindset appeared to play an important role in mitigating the difficulties of care/the uncertainty of the role through strengthening resilience.

Parent carers living in India in Sadath et al. (2014) and carers that identify as British Pakistani living in the U.K. in Penny et al. (2009) expressed uncertainty in relation to south-Asian cultural and societal norms. For example, parent carers in Sadath et al. (2014) worried about their child’s capacity for future romantic relationships, particularly their marriageability, and those in Penny et al. (2009) worried about their child’s ability to care from them as they became older.

Shame and Stigma

Another theme that emerged was caregivers’ experiences of shame and stigma. The siblings in Sin et al. (2008) and Sin et al. (2012) discussed seemingly painful feelings of embarrassment, denial and shame that appeared to arise from the stigma associated with FEP. This made some siblings reluctant to disclose their family circumstances to teachers and friends within their own network. Siblings under 16 frequently reported keeping their siblings’ FEP a secret from others for fear of judgement and a lack of understanding.

Similarly, feelings of embarrassment were also reported by caregivers in McCann and colleagues (2011) who felt that they had loss social status as a result of their unwell loved one. This seemed to stem from others having witnessed their loved one in the midst of a crisis. These painful feeling led to caregivers adopting a ‘secretive’ approach to coping with caring for their relative. Carers minimised contact with others and isolated themselves, and this was particularly true for caregivers from

ethnic minority groups. For example, caregivers in Saddath et al. (2014) living in India felt concerned about the implications of others knowing about their relative's FEP. This stigma prevented caregivers from engaging in certain parts of the caregiver role, such as taking their loved one with FEP outside of the family home and seeking help from services. Isolation as a result of stigma was also reflected in the results from McCann, Lubman & Clarke (2011) due to judgment and lack of understanding of others around mental health difficulties. For the caregivers in Penny et al. (2009) in the initial phases of FEP, caregivers realized that their loved one was becoming unwell when their behaviour fell out of line with expected social norms, such as communicating politely with others.

The Emotional Demands of Care

This theme synthesises the emotional difficulty that came with the role of being a caregiver from all seven papers. A range of emotions were discussed by the participants across the papers, including feeling burdened, overwhelmed, drained, responsible, and a sense of loss amongst other complex feelings. Indeed, complex and contradictory feelings were reported by the siblings in Sin et al. (2012). This took the form of resentment towards their sibling with FEP and subsequent feelings of guilt for feeling this way at all. For some siblings, this appeared to stem from a sense of feeling neglected by their parents. 'Well' siblings still wanted to elicit care from their parents, but the majority of their parents' time was taken up by caring for their sibling with FEP. They appeared to 'understand' that their sibling with FEP required more care, but understandably still hoped for their own needs to be met. Feelings of being burdened by their unwell sibling and feeling stressed also came to light, which was also reflected by the siblings in Sin et al. (2008). Carers in McCann et al. (2011) described care as a 'burdensome responsibility' and 'constant worry' that led to

feeling emotionally depleted and carers in Kumar et al. (2019) reflected similar feelings of pervasive worry. Caregivers in Sadath et al. (2014) and Kumar et al. (2019) also experienced significant distress in caring for their relative such as feeling vulnerable, confused, scared, and helpless when their relative was behaving in a violent or demanding way. Parental caregivers, in particular mothers, felt emotional distress in the form of responsibility of care for their son or daughter with FEP, as exhibited by parents in Penny et al. (2009) and McCann et al. (2011). This enhanced sense of responsibility in female caregivers increased feelings of burden in the caregiving relationship, and this feeling was exacerbated when other family members placed blame on the female caregiver when something went wrong. Penny et al. (2009) reported an initial profound sense of loss after a 'sudden realisation' that their family member was experiencing psychosis, and this appeared to be akin to feelings of grief and bereavement.

For those in Kumar et al. (2019) loss and mourning were felt in relation to their unwell relative's future and the prospect of deviating from the expectations that they had for their family member. For caregivers in Lavis and colleagues (2015) loss was experienced in a slightly different way. Instead, loss manifested in relation to the caregivers' lives and identities being reshaped by the caregiver role. There was a sense of the caregiver role having 'taken over', even after their relative had recovered because 'embodied vigilance can be hard to let go of' (Lavis et al., 2015, p. 138). Similarly, this feeling of 'constant vigilance' was also reported in McCann et al. (2011) and was accompanied by feelings of sadness. This sadness appeared to stem from the transition of their role from family member to caregiver that was sometimes a frightening experience with new responsibilities and obligations. Lavis et al. (2015) further elucidated the experience of loss for parent caregivers. Parents seemingly felt

their child had regressed to an infantile state and this brought a range of emotions including sadness and entrapment. In Sadath et al. (2014) the wellbeing of caregivers was also reportedly compromised due to sleep disturbances.

The Practical Demands of Care

There were some similarities and some differences between the studies in relation to the practical side of the caregiving role. For example, Siblings in Sin et al. (2008) and Siblings in Sin et al. (2012) reported that a key element of their role was to provide normalising activities, such as socialising, keeping active, and communicating with their sibling in the same way they did before they became unwell. Siblings also added that their role included supporting their parents, liaising with services, emotional support, and practical support. In Sadath et al. (2014), the practical demands of caregiving often fell to sibling caregivers such as washing, cooking, and cleaning. In the cultural context of the Indian families interviewed it felt particularly important for the siblings to support their family unit as a whole during periods of adversity.

A sense of needing to provide normality was also shared by the caregivers in Lavis et al. (2015). For example, caregivers felt it was important to provide normality by holding continuity and structure for their loved one. A significant part of the caregiver role seemingly included tasks such as going shopping and generally supporting their loved one with the tasks of daily living. However, this was sometimes challenging as caregivers were tasked with maintaining this sense of calm, whilst managing the 'flux, hurry, and rupture' of FEP (Lavis et al., p. 137).

Some caregivers reflected upon a more general sense of needing to 'be there' for their loved one whenever they may need them. Understandably, this led to the role feeling 'full time'. Family caregivers in Penny et al. (2009) echoed this sense of care

feeling ‘full time’, with one family disengaging from all other responsibilities for one year to take their child to Pakistan in hopes of reaching ‘recovery’. As highlighted by McCann et al. (2011), being a family caregiver can alternate between periods of high demand during challenging phases of psychosis and periods of relative calm during ‘well’ phases. The physical demands of care felt particularly heavy for female caregivers, who seemingly felt overwhelmed by trying to balance different facets of life such as family, work, and other commitments, alongside their caregiving role (McCann et al., 2011).

Significant financial challenges for carers were mentioned in two papers (Sadath et al., 2014; Kumar et al., 2019). In Sadath et al. 2014, families experienced financial burden, partly due to seeking expensive faith-healing practices in the first instance, when their relative first experienced FEP and due to the loss of work as a result of caregiver demands. In addition, families financial resources were also depleted for a range of reasons include the demands of the caregiving role itself, old age, and being widowed. Similarly, in Kumar et al. (2019) families reported losing their daily wage to attend follow up appointments and the cost of medication.

Critique of Papers

Overall, six out of seven papers included in this review were of good methodological quality, according to the CASP tool (2018). These six studies provided clear aims and appeared to have appropriately selected qualitative methodologies for the subject matter being investigated. All papers sought to explore the subjective experiences of family members and significant others caring for a loved one during FEP.

Table 5: Summary of critiques

Study	Design	Inclusion/Exclusion Criteria	Results	Limitations	CASP Qualitative Criteria
Kumar et al., 2019	Qualitative	<p>Inclusion as follows:</p> <ul style="list-style-type: none"> Caregivers of clients 15-25 years old 18 + years old Psychosis duration of 3 month – 2 years Living with client for 1 + year No chronic mental health difficulties Not other caring responsibilities 	<ul style="list-style-type: none"> Broad themes and subthemes from focus groups clearly presented with frequency of responses included. Supporting quotations provided. However, each theme not discussed in much detail. Could benefit from greater depth of findings. 	<p>Limitations discussed by researcher:</p> <ul style="list-style-type: none"> Sample mostly male. May not be representative of other geographical locations. Limits of group Methodology. 	<ol style="list-style-type: none"> Clear Aims? Yes Appropriate methodology? Yes Appropriate design? Yes Appropriate recruitment? Yes Data collection addresses issue? Yes Researcher position considered? No Ethical issues considered? Yes Data analysis rigorous? Yes Clear findings? Yes Valuable? Yes
Lavis et al., 2015	Qualitative	<ul style="list-style-type: none"> Caregivers of young people with FEP (aged 14-35 years) Carers 	<ul style="list-style-type: none"> Themes clearly presented and discussed thoroughly Supporting 	<ul style="list-style-type: none"> Carers predominantly white British. May not be representative of cares more 	<ol style="list-style-type: none"> Clear Aims? Yes Appropriate methodology? Yes Appropriate design? Yes Appropriate recruitment? Yes Data collection addresses issue? Yes

		nominated for participation by the loved one they care for.	quotations included	broadly <ul style="list-style-type: none"> Carers nominated by loved one 	<ol style="list-style-type: none"> 6. Researcher position considered? Yes 7. Ethical issues considered? Yes 8. Data analysis rigorous? Yes 9. Clear findings? Yes 10. Valuable? Yes
McCann et al., 2011	Qualitative	<ul style="list-style-type: none"> First time primary care giver to young adult (15.24 years) with FEP. Caregiving role for 3+ years English speaking 	<ul style="list-style-type: none"> Themes clearly and thoroughly presented. Supporting quotations Clear and accessible structure 	<ul style="list-style-type: none"> Limits of qualitative methodology (representative of individuals). Recruitment through EIS case managers. Predominantly female sample. 	<ol style="list-style-type: none"> 1. Clear Aims? Yes 2. Appropriate methodology? Yes 3. Appropriate design? Yes 4. Appropriate recruitment? Yes 5. Data collection addresses issue? Yes 6. Researcher position considered? No 7. Ethical issues considered? Yes 8. Data analysis rigorous? Can't tell 9. Clear findings? Yes 10. Valuable? Yes
Penny et al., 2009	Qualitative	<ul style="list-style-type: none"> Slightly unclear inclusion criteria. Self-defined as Pakistani or British Pakistani Families receiving care 	<ul style="list-style-type: none"> Clear themes and easy to follow. Themes and subthemes clearly displayed. Embedded parts of transcript 	<ul style="list-style-type: none"> Limitations not discussed by researcher. 	<ol style="list-style-type: none"> 1. Clear Aims? Yes 2. Appropriate methodology? Yes 3. Appropriate design? Yes 4. Appropriate recruitment? Can't tell 5. Data collection addresses issue? Yes 6. Researcher position considered? No 7. Ethical issues considered? Yes

		from EIS and caring for family member with FEP.	provide context for themes.		8. Data analysis rigorous? Yes 9. Clear findings? Yes 10. Valuable? Yes
Sadath et al., 2014	Qualitative	<ul style="list-style-type: none"> • FEP = duration of less than 5 years. • Carers 18+ years old. • Family member or relative • Living in same home • Spoke English, Kannada, Tamil, or Malayalam. 	<ul style="list-style-type: none"> • Embedded quotations. • Results discussed in depth. • Clear and defined themes. 	<ul style="list-style-type: none"> • Relationship not established between categories. 	<ol style="list-style-type: none"> 1. Clear Aims? Yes 2. Appropriate methodology? Yes 3. Appropriate design? Yes 4. Appropriate recruitment? Yes 5. Data collection addresses issue? Yes 6. Researcher position considered? No 7. Ethical issues considered? Yes 8. Data analysis rigorous? Can't tell 9. Clear findings? Yes 10. Valuable? Yes
Sin et al., 2008	Qualitative	<ul style="list-style-type: none"> • Siblings (aged 16-35 years) who's brother or sister has FEP under care of local 	<ul style="list-style-type: none"> • Themes thoroughly presented. • Accessible and clear. • Could benefit 	<ul style="list-style-type: none"> • Research still on going – publication reports initial findings. • Possible biased 	<ol style="list-style-type: none"> 1. Clear Aims? Yes 2. Appropriate methodology? Yes 3. Appropriate design? Yes 4. Appropriate recruitment? Yes 5. Data collection addresses issue? Yes

		EIPS in the UK.	from demonstrating process of analysis more clearly.	sampling. • Higher proportion of female siblings.	6. Researcher position considered? No 7. Ethical issues considered? Yes 8. Data analysis rigorous? Can't tell 9. Clear findings? Yes 10. Valuable? Partly
Sin et al., 2012	Qualitative	• Siblings (aged 11-35 years old) with brother or sister of individuals with FEP.	• Embedded quotations. • Clear and detailed themes. •	• Higher proportion of female siblings. • Possible biased sampling related to recruitment method.	1. Clear Aims? Yes 2. Appropriate methodology? Yes 3. Appropriate design? Yes 4. Appropriate recruitment? Yes 5. Data collection addresses issue? Yes 6. Researcher position considered? No 7. Ethical issues considered? Yes 8. Data analysis rigorous? Can't tell 9. Clear findings? Yes 10. Valuable? Partly

Research Reflexivity

Lavis et al. (2015) was the only study to consider research reflexivity, which is a strength of this paper. No other studies discussed researcher reflexivity, which is therefore a limitation of the remaining studies. Reflexivity is particularly important in qualitative research due to its emphasis on interpretation and emergent themes, with no specific formula to carry out qualitative research (Watt, 2007). Without considering their own positions, the authors may have been unable to consider how their assumptions impacted the research process.

Data Analysis

All studies were qualitative but the chosen method of qualitative analysis varied between papers: Grounded Theory (Kumar et al., 2019), Responsive Reader Method (Sin et al., 2008; Sin et al., 2012), IPA (McCann, Lubman, & Clark, 2011; Penny et al., 2009) Content Analysis (Sadath et al., 2014), and Iterative Thematic Analysis (Lavis et al., 2015). All seven papers included an in-depth description of the analytic process. However, compared to the other papers Kumar et al. (2019) was slightly weaker in that they included very few quotations in the main body of the text. In addition, the themes did not appear to be explored particularly deeply. This provided the reader with a limited sense of the participants' subjective experiences of caring for their loved one with FEP. However, the other elements of the paper pertaining to the analytic process were well detailed. This included a copy of the interview schedule and a detailed account of its development with input from mental health professionals and experts by experience. They also included a table of themes and subthemes with frequencies representing the number of participant responses for each category.

Participants

Sample sizes varied between papers from the smallest of ten participants (Sin et al., 2008) and the largest sample of eighty participants (Lavis et al., 2015). The majority of studies included predominantly female samples, with the exception of Kumar et al. (2019) (n = 37, 57% male participants) and Sin et al. (2012) (female participants n = 5, male participants n = 20). This may mean that the data is perhaps more reflective of the overall experience of female caregivers, which could limit the generalizability of the findings of this review.

The inclusion criteria varied between papers, with some studies having more stringent and selective criteria than others in relation to FEP and to the participant caregivers. All papers specifically examined the caregivers experience during FEP, but this was specified differently across papers. This was to be expected, as the definition of FEP can vary across clinical and research settings (Breitborde et a., 2009, p.2).

The only inclusion criteria in Lavis et al. (2015) were that the participants had to be under the care of a local EIS. This was also the case for Sin et al. (2012), Sin et al. (2008), and Penny et al. (2009).

Other studies inclusion criteria were related to the duration of the relative's FEP. For example, Kumar et al. (2019) stated that the duration of psychosis had to be between three months to two years, and under the care of services for at least three months. The mean duration of FEP from the cohort of participants was 12.78 months. Sadath et al. (2014) recruited eleven family caregivers through inpatient and outpatient hospitals in India and specified that the duration of FEP should be less than five years (mean duration 6 - 48 months).

McCann et al. (2011) specified that to qualify for inclusion family caregivers must have provided care for a maximum three years. They also considered the limitations of their sample. For example, they used a volunteer sample, which may have been made up of actively engaged caregivers only. The sample may therefore have lacked generalizability due to qualitative nature of research and homogeneity of sample.

Discussion

This review aimed to explore the experience of family members and significant others caring for a loved one during FEP. Qualitative literature within this area that seeks to understand this experience is limited, thus a review of the qualitative literature to synthesis the experience was required. The research papers included in this review described the different aspects of the caregiving role that were amalgamated into five themes. The themes will be discussed in further detail in relation to the wider existing literature and theory.

The Positives of Care

This first theme highlighted the positives within the experience of caring for a loved one with FEP. The positive aspects of caregiving that were reported by some of the participants ranged from enhanced bonds with their loved one with FEP, a sense of personal growth and development, increased resilience (both personally and as a family unit), and an increased sense of cohesion within the family system. These findings resonate with existing literature that demonstrates the caregiver role during FEP does indeed have positive aspects, including increased compassion, understanding, empathy, and a sense of renewed closeness between family members (Coldwell et al., 2011). In recent years, research has begun to play attention to these

more positive aspects of caregiving for a loved one experiencing psychosis to understand the experience on a broader level (Kuipers et al., 2010).

The Future Is Uncertain: Coping Mechanisms

This theme highlighted the uncertainty in relation to the future that came with the caregiver role, which lead caregivers to feel unsettled or anxious. This uncertainty impacted caregivers from different papers differently. For example, this ranged from the experience of caregiving feeling like an unpredictable ‘rollercoaster’ in McCann et al. (2011) to fears that their other children may develop FEP in Kumar et al. (2019). To cope with the uncertainty and challenges of being a caregiver, a range of coping mechanisms were seemingly employed by the participants across the studies. Indeed, research shows that caregivers employ a range of emotional, practical, and spiritual coping mechanisms to manage the experience of caring for a loved one with FEP (Tennakoon et al., 2000). A large-scale review by Jansen and colleagues (2015) found a link between the level of distress a caregiver experiences in the caring relationship and psychological factors such as avoidant coping and emotional over involvement, which highlights the importance of adaptive coping mechanisms for family caregivers. The coping mechanisms in Penny et al. (2009) were seemingly adaptive. Caregivers turned to religion as way of coping with distress, which allowed caregivers to give control to a higher power whilst simultaneously influencing the outcome (e.g., through prayer). This appeared to be an effective strategy to manage the emotional challenges and uncertainty associated with caregiving. For caregiver siblings in Sin et al. (2008), witnessing their siblings experience FEP seemingly evoked an uncomfortable realisation that the future is uncertain. This led to avoidant coping styles such as distancing oneself from their sibling. This avoidant coping style also appeared to impact other interpersonal relationships. For example, this altered

some of the siblings' desires for the future, such as no longer wishing to have children. It could be argued that making such decisions for one's future is a protective mechanism and allows caregivers to gain a sense some control over their future to obtain 'safe certainty' (Mason, 2022).

The Cognitive Model of Caregiving (Kuipers et al., 2010) is a model of informal caregiver relationships within the context of psychosis and could help to explain the differences in caregiver coping styles. The model posits that the caregiver's appraisal of FEP has a direct impact on their coping style. For example, if the caregiver views the psychosis as 'unusual' and outside the individual's typical patterns of behaviour, this signals that something is wrong. Subsequently, the caregiver views their loved one as needing care and support. This type of caregiver still may experience stress and worry, but they are more likely to adopt a non-avoidant coping style and hold optimism for the future. This is likely to have better outcomes for the caregiver's wellbeing and for their loved one. This type of caregiver appraisal and coping style appears to resonate with the caregivers from McCann et al. (2011) who adopted adaptive coping styles and were able to hold hope for the future, which, in turn, acted as a buffer for distress. Indeed, literature demonstrates that the level of distress the caregiver feels is a result of their appraisal and coping style, as opposed to the severity of the psychosis itself (Gupta & Bowie, 2018). Again, this highlights the importance of caregiver resilience which can have positive outcomes for both the caregiver and the client.

Alternatively, if the caregiver appraises the psychosis as their loved one's own fault and place blame for the psychosis onto them (e.g., viewing them as 'lazy' which led them into difficulty), this caregiver is then likely to reject their loved one, adopt an avoidant coping style, and feel pessimist about the future. This type of caregiver style

appeared to resonate with the caregivers in Lavis et al. (2015) and Penny et al. (2009). It is also common for this type of caregiver style to be adopted by siblings, which resonates with some of the avoidant coping styles for sibling caregivers in Sin et al. (2008) and Sin et al. (2012).

Shame and Stigma

Central to the experience of caring for a loved one experiencing FEP appeared to be shame and stigma. Stigma can be defined as “an attribute that makes a person different from others in a social category, and it reduces the person to a tainted or discounted status” (Goffman, 1997, p. 133). Goffman (1997) posits that the presence of stigma can lead to anxious social interactions that feel uncomfortable for both parties. These uncomfortable interactions that stem from stigma may explain why some caregivers in the studies chose to avoid disclosing their family circumstances to others and adopted ‘secretive’ coping styles. A sense of a feeling ‘tainted’ and of ‘discounted status’ may partly explain why the caregivers in McCann et al. (2011) felt a ‘loss of social status’ as a result of their loved one’s FEP. A large systematic review by Yin and colleagues (2020) found that in the context of psychosis ‘associative stigma’ had significant impacts for caregivers in various ways. Associative stigma can manifest as social isolation towards caregivers, which in turn caused low self-esteem and chronic stress. Consequently, caregivers may experience a shrinkage of their social networks as they are avoided by others. This may explain some of the caregivers’ experiences within the studies, and perhaps also explains the reluctance of some caregivers to disclose their circumstances to others.

It is important to consider the findings from Saddath et al. (2014) living in Bangalore, India. Literature shows that individuals from south-Asian countries are at increased risk of developing psychosis in comparison to the majority population

(Bourque et al., 2011). In addition to the increased risk of psychosis, shame and stigma may also be particularly problematic amongst British south-Asian individuals experiencing psychosis and their caregivers. There is an increased likelihood of rejection from the community, which can lead to delays in help-seeking and further fuel feelings of shame (Islam et al., 2021). There was also a sense of needing to ensure that for outsiders looking in, the family needed to appear as though they were functioning well. This seemed to stem from a desire ingrained within this culture to avoid bringing shame on the family (Vyas et al., 2021).

The Emotional Demands of Care

This theme synthesised the emotional demands associated with the caregiver role which were multiple and complex. This ranged from feelings of loss and burden to a sense of constant anxiety and ‘vigilance’. It was therefore evident from the studies that the experience of providing care for a loved one with FEP can be very challenging. Family units are complex, and the way that they function is a complex process that continuously changes over time (Gumley et al., 2013). Family Systems Theory (FST) may help to explain the emotional impact of FEP and caregiving on family members. FST posits that families are one interdependent emotional unit (Bowen, 1966). Thus, the emotions and needs of one family member will directly impact all other family members within the unit. The siblings in Sin et al. (2008) and Sin et al. (2012) were affected by their sibling’s FEP in several ways which is likely due to witnessing their sibling experience great difficulty (e.g. drug use, suicidality, hospital admission) (Bowman et al., 2014). Notably, there was a complex sense of resentment and guilt for the changes that had been brought into the family unit. Their relationship to their parents had changed because of their sibling with FEP requiring more care and attention within the unit. Furthermore, carers in Kumar et al. (2019) felt very concerned about their other children

within the family unit developing psychosis. In the context of FST, this fear makes sense as the struggles of one family member directly impact the other.

Limitations

One limitation of this review is that it did not include quantitative literature within the psychosis and family caregiver space. However, the majority of research within this area is quantitative, and it is likely that including quantitative papers would have taken this review outside the scope of a doctoral research study.

A further limitation is the use of qualitative literature. The studies included provide a ‘snapshot’ in time of families, with no further detail about how the families interact with each other and other contextual factors that may be impacting the family unit.

Clinical Implications

This review has highlighted the different coping mechanisms that are used by caregivers of loved ones with FEP and has considered the literature in relation to adaptive and non-adaptive coping mechanisms. It may be helpful for EIS to provide further psychoeducation to family members around coping mechanisms, particularly considering the positive impact adaptive strategies can have on both the caregiver and their loved one.

A further clinical implication relates to shame and stigma, which appeared to be a significant element of the caregivers’ experiences. This has a wide range of impacts including delaying help seeking and reduced social support for caregivers. Shame also appeared to be particularly relevant for those from minority ethnic groups due to social and cultural norms within this population. It may be important for EIS to become more culturally sensitive services and take this into consideration, which could be done through targeting stigma (Mui et al., 2019). For example, EIS could

generate an anti-stigma campaign (Kleinman et al., 2009; Chen et al., 2016) that targets stigma in a culturally specific way and attempts to increase access to services. This is particularly important as those from minority ethnic groups are disproportionately impacted by psychosis. Additionally, it may be helpful for EIS to simply hold space to listen to the concerns of caregivers, in turn this may increase the sense of support the caregiver feels and may encourage further help seeking on the part of the carer.

Research Implications

This review has synthesized the overall experience of family members and significant others providing care for a loved one with FEP. It may be helpful for a review to be carried out on caregiver coping styles and the impact that this has on the caregiver and their loved one being cared for. This could inform the development of interventions specific to carers under the care of EIS, potentially improving outcomes for them and their loved ones. Although not examined explicitly within this review, it may be helpful for a review to be carried out on the experiences of British Asian families living in the U.K. to assess how their experiences of caregiving and needs differ from white British families. This could support services to develop more sensitively cultural practices and enhance communication between families and services, particularly as the help-seeking process appears to be delayed within this demographic.

Conclusion

The review aimed to synthesis the literature in relation to the overall experience of family members and significant others providing care for a loved one with FEP. Literature shows caregivers play an important role in good outcomes for their loved one, but the experience of caregiving can be distressing. It was appropriate to

synthesis the qualitative literature within this area to gain a deeper understanding of the overall experience of care. This review included families from several countries and cultures including the UK, Australia, and India. The overall experience of caregiving can be broken down into five broad themes: the positives of care, the future is uncertain, shame and stigma, the emotional demands of care, the physical demands of care. It is evident that the care experience can be challenging, but there is also a positive side to caregiving during FEP. It is hoped that this review can inform service provision and further research can be carried out in relation to the caregiver coping styles and their subsequent impact on caregivers and their loved one, and the experiences of minority ethnic families caring experiences.

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Section B

**The experience of attempting to create organisational change: An Interpretative
Phenomenological Analysis of the experience of clinicians integrating Open
Dialogue to psychosis services within the National Health Service**

Word Count: 8,000 (854)

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Abstract

Background: Interest in the Open Dialogue approach continues to grow around the world and UK are among the countries assessing the feasibility of integrating the approach to the existing structure of mental health services. Very few studies have explored the experience of clinicians attempting to bring about organisational change to integrate the approach to NHS psychosis services. **Method:** Seven clinicians working within NHS early intervention in psychosis services were interviewed. **Analysis:** The interviews were analysed using Interpretative Phenomenological Analysis (IPA). Four group experiential themes emerged from the data: 1) Recalibration journey, 2) The redistribution of power, 3) Anxiety and resistance to change, 4) Creating the change. **Discussion:** the findings are discussed with reference to existing literature and organisational change theory. Clinical and research implications are discussed in relation to change processes with the current NHS system.

Introduction

A Brief History of Open Dialogue

Throughout the 1980s in Finland a large-scale transformation of public mental health services, The Finnish National Schizophrenia Project, took place to improve the care received by those experiencing a mental health crisis (Seikkula et al., 2001). Services began to adopt a ‘Needs Adapted Approach’ (NAA) that emphasised early intervention, building a therapeutic rapport between families and clinicians, training staff in psychotherapy, and tailoring treatment plans to the client and their families to meet their varied and idiosyncratic needs (Seikkula et al., 2001). There was a particular emphasis on tailoring treatment to meet the needs of clients experiencing psychosis (Seikkula et al., 2001) due to the complexity and heterogeneity of the phenomena for the individual (Bergström et al., 2018). In a small province of Western Lapland with a population of 63,000 inhabitants (Bergström et al., 2017), NAA was further innovated by Jaakko Seikkula, and thus the Open Dialogue (OD) approach was subsequently developed (Seikkula et al., 2001; Seikkula, 2003; Seikkula & Oslén, 2003). A gradual shift took place towards successfully organising all mental health services within the province in line with the seven core principles of OD throughout the 1990s (Bergström et al., 2018).

An Overview of OD

OD is a social network based, early intervention approach that aims to begin work with people experiencing a mental health crisis within their individual social networks within twenty-four hours of referral (Bergström et al., 2017). The seven core principles that underpin the approach are: immediate help, a social network perspective, flexibility and mobility, responsibility, psychological continuity, tolerance of uncertainty, and dialogue (Bakhtin, 1984; Seikkula et al., 2001). It is both

a way of organising an entire system of mental healthcare, as is the case in Western Lapland (Bergström et al., 2017), and a therapeutic intervention (Freeman et al., 2019; Hendy & Pearson, 2020). OD emphasises outpatient and psychotherapeutic approach with a view to delaying treatment through medical means, such as hospital admission or neuroleptic medication (Bergström et al., 2017).

Network Meetings (NMs) are the key means of delivering care within the OD framework (Pilling et al., 2022) and are comprised of the client, key members of their social network, and the professionals involved in their care. NMs are a forum for open and transparent conversations that are viewed as a form of therapy for psychological distress (Seikkula, Alakare & Aaltonen, 2001). The client and their network are integrated into discussion of all issues throughout the treatment process, generating a therapeutic dialogue between all parties involved (Bergström et al., 2017; Seikkula & Olsen, 2003) and allowing the development of shared language to understand the client's difficulties (Bergström et al., 2017; Seikkula, Alakare & Aaltonen,). Meetings have no pre-planned themes or agenda, allowing meaning to be constructed by the language that the client and their network members bring, to immerse professionals within their phenomenological world (Seikkula, Alakare & Altonen, 2001). Treatment decisions are not based upon psychiatric diagnosis (Seikkula, Alakare & Aaltonen, 2001) and the client's understanding of their experiences take precedence over the professionals' formulation of the problem (Anderson, 2002). Nevertheless, many of the experiences that lead to the perception of a mental health crisis could attract the label 'psychosis'.

Epistemological and Philosophical Underpinning of OD

OD is underpinned by social constructionism theory and Bhatkin's concept of dialogism (Bakhtin, 1984). Constructivism is a way of building knowledge and creating meaning, based on the notion that no knowledge is neutral or objective. Rather, knowledge is created through a dynamic process between individuals and the world around them, with a particular emphasis on the role of language within this process of meaning making (Bakhtin, 1984). Language within a social context mediates and supports the construction of concepts or knowledge (Hirtle, 1996). Within the context of OD, mental health difficulties are therefore viewed as socially constructed, and new meanings are reformulated with each conversation in the space between families and professionals during NMs (Pavlovic et al., 2016). OD can also be situated within draws on a critical psychology/psychiatry framework, in that it resists imposing medical ways of understanding mental distress, including diagnostic labels and medical terminology.

Bringing Open Dialogue to the National Health Service

Promising evidence demonstrates good clinical outcomes for OD in Finland that are stable over time, including a reduced need for mental health services, long-term cost saving, fewer relapses, fewer hospital days, and less use of neuroleptic medication when compared to treatment as usual (Aaltonen et al., 2011; Bergström, et al., 2018; Pavlovic et al., 2016; Seikkula et al., 2003; Seikkula et al., 2006; Seikkula, Alakare & Aaltonen, 2011). Understandably, interest in OD continues to develop across the world and the U.K. is assessing the feasibility of implementing the approach into the existing structure of the National Health Service (NHS) (Tribe et al., 2019; Pilling et al., 2022). The ODDESSI trail (Open Dialogue: Development and Evaluation of a Social Network Intervention for Severe Mental Illness) is a large-

scale research project currently taking place across five NHS Trusts, with the first results due in 2024 (Pilling et al., 2022). Evidence suggests that OD may provide an important framework for the delivery of mental health services within the U.K. (Razzaque & Wood, 2015) and may be a welcome challenge traditional working roles and professional hierarchies that exist within the NHS (Freeman et al., 2019). However, research suggests that factors such as existing organisational structures, culture, and power dynamics may be difficult to change and therefore disruptive to the integration of OD (von Peter et al., 2023). This may make integration a highly complex task (Ellis et al., 2018).

Complexities of integrating OD

OD is a 'radically different approach' to the existing framework for delivery of care within the NHS, which often assume a medical model approach to mental health care (Wates et al., 2022). Integration of OD may therefore be perceived as an unwelcome challenge to the status quo in conventional, medically led mental health services by non-OD trained clinicians (Razzaque & Wood, 2015; Tribe et al., 2019) and it is currently unclear how to align the differing paradigms harmoniously within services (Lennon et al., 2022).

The implementation of OD in Lapland took place gradually, but deliberate and fundamental changes were made to the structure, organisation, and management of mental health services to assimilate OD (Lennon et al., 2023) including training in the approach for all healthcare staff, regardless of professional (Seikkula, Alakare & Aaltonen, 2001). Such steps are yet to be taken within U.K. services to create organisational change around the OD approach, and a recent review of OD in the UK highlighted that the important context in which OD is being implemented into

services, such as the management and culture within the organisation, is often absent amongst published studies (Buus et al., 2021).

Research on the effective innovation of mental health services to create change in line with OD remains limited (Lennon et al., 2023) and Lennon and colleagues (2023) highlight that this makes it challenging to understand how best to innovate and go about implementation of the approach with organisations, and what this experience is like for clinicians.

Healthcare organisations such as the NHS are intricate and dynamic systems that are characterised by complex behaviours and processes (Harrison et al., 2021). Literature suggests that effective change management is essential for leaders to bring to organisations to effect change, innovate, and improve healthcare. However, attempts to innovate and bring change within healthcare organisations often fail (Harrison et al., 2021) and as previously noted, the existing structures of the NHS have not been adapted to adopt the approach, as is the case in Lapland.

The Transtheoretical Model of Change (TMM) was developed by Prochaska and colleagues (2001) and builds on arguably the most influential model of individual change; the ‘Stages of Change Model’ which is the central construct the model (Grimley et al., 1994). The model focuses on intentional change and posits that change occurs through 5 stages: pre-contemplation (not yet acknowledging the need for change), contemplation (considering change), preparation (getting ready for change), action (the process of changing), and maintenance (maintaining the change). Although it has been criticised for the generalisation of a ‘simplistic’ individual theory of change to more ‘complex’ organisational change, the authors argue that the TMM can be helpfully applied to organisations as a whole *and* to the individual organisation members (Prochaska et al., 2001). The authors argue that this is where

the strength of the model lies because, ultimately, “change in individual organisation members behaviour is at the core of organisational change” (Prochaska et al., 2001). Indeed, if most members of an organisation are in the early stages of change (e.g., “pre-contemplation” or “contemplation”), the desired change is of course unlikely to occur, and resistance is likely to be met. OD-trained clinicians looking to integrate OD are, arguably, looking to create organisational change within an organisation that may not yet be ready. Existing literature has yet to draw on the organisational change theoretical literature to explore this experience and elucidate its associated successes and challenges within the context of NHS EIS.

Rationale and research questions

Arguably, facilitating the adoption of OD within services dominated by the medical model, where changes towards a paradigm shift may not have been considered, is a complex task. OD-trained clinicians may be unable to simply begin practicing OD without beginning the process of change to the wider organisation and it is currently unclear how clinicians may bring about this change that fosters the adoption of OD and what this experience is like. The evidence base pertaining to the implementation of OD in the UK remains limited (Hendy & Pearson, 2020). To the author’s knowledge, research has yet to explore this gap in the literature and there is a lack of qualitative literature specifically within this gap. With interest in OD continuing to develop in the UK, it could be argued that research that explores this is particularly important at the present time. Therefore, the following research questions were explored:

1. What were the clinicians’ experiences of integrating OD to NHS psychosis services?

2. What challenges (if any) did clinicians experience when integrating OD and bringing change to NHS psychosis services?
3. What factors (if any) did clinicians feel supported the integration of OD and bringing change to NHS psychosis services?

This project is grounded within NHS values, including ‘Commitment to Quality Care’ and ‘Improving Lives’. As previously noted, the literature demonstrates good clinical outcomes for OD in Finland and there is some concern about the ability of current NHS services to meet the individual needs of clients. It is hoped that the findings of this paper may be able to support clinicians with the process of integration and may inform service provision within NHS psychosis services. This may improve outcomes for clients.

Method

Design

A qualitative design was selected as the most appropriate to cultivate rich and meaningful data from participants. This study used Interpretative Phenomenological Analysis (IPA) of semi-structured interviews. IPA is a participant-orientated approach that is concerned with the study of human lived experience (Smith, Flowers & Larkin, 2009; Alase, 2017) and draws on three areas of philosophy of knowledge to construct meaning: phenomenology, hermeneutics, and ideography (Shinebourne, 2011). IPA is situated within social constructionism, emphasising ‘idiographic subjective experiences’ (Biggerstaff et al., 2008, p. 215) and holding a ‘critical stance towards our taken-for-granted ways understanding of the world and ourselves’ (Burr, 2015, p.3). IPA therefore allows meaning to be derived directly from the individual’s unique

perception of reality that is deeply intertwined and inseparable from the environmental context in which these experiences take place. A key factor in choosing IPA was “double hermeneutic” theory of interpretation. The double hermeneutics approach in IPA describes the process by which the researcher makes sense of the participant, who is making sense of their experience. This means that the participant’s sense-making is first order, and the researcher’s is second order. It is important to note that the analyst’s interpretation is not prioritised over the participant’s sensemaking; rather, the research offers a different perspective on the data that the participant may be unable to (Smith, Flowers & Larkin, 2009) making the analysis deeper and more meaningful. This process of multilayered analysis sets IPA apart from different qualitative methodologies, such as thematic analysis.

Recruitment

Participants were recruited through Open Dialogue UK, an organisation set up in 2012 that provides workshops and training courses for clinicians to support the implementation of OD within public mental health services in the UK. The programme co-ordinator from Open Dialogue UK sent out a blanket email advertising the study and contact details for the lead researcher to clinicians that had completed either training course. Clinicians that were interested in participating emailed the lead researcher and were subsequently sent the information sheet (Appendix 1), consent form (Appendix 2), and given the opportunity to ask any questions. An appointment was made for the interview to be held virtually for clinicians that confirmed they would like to participate.

Inclusion Criteria

The participants met the following inclusion criteria:

- Mental health professional from any discipline.
- Clinicians practicing within an NHS psychosis service at the time of the study.
- Completion of the one-year or three-year OD training courses provided by Open Dialogue UK.

Participants

A homogenous sample of participants is key in qualitative research to gain a 'rich and deeply descriptive' (Alase et al., 2017, p. 13) understanding of the phenomena being studied (Alase et al., 2017). Participants were recruited purposively, based on life experience homogeneity (Robinson, 2014). In this instance, clinicians' experience of integrating OD to NHS psychosis services. Sample sizes in IPA studies are influenced by both theoretical and practical considerations (Robinson, 2014). Research with an idiographic focus typically includes smaller sample sizes, between three and sixteen, to allow for a thorough analysis to be conducted whilst preventing the voices of individuals becoming lost within the data (Robinson, 2014). Taking this into consideration along with the parameters of a doctoral level research project, a recruitment target of seven to ten participants was agreed upon with both research supervisors. A total of nine clinicians emailed the lead researcher expressing interest. However, one clinician made no further contact with the researcher, and one clinician informed the researcher that they were unable to make the time for the interview. One further blanket email was sent out by the Open Dialogue UK programme co-ordinator, but no further clinicians made contact. Considering the time constraints of the project, the lead researcher was keen to move forward with the project with a total of seven participants.

Table 1: Participant Data

Pseudonym	Role	Service Type	Training Course	Year training Completed
Julie	Systemic Family Therapist	Early Intervention in Psychosis	One Year Foundation Course	2021
Derek	Consultant Clinical Psychologist	Early Intervention in Psychosis	Three Year Course	2018
Alexander	Systemic Family Therapist	Early Intervention in Psychosis	Three Year Course	2017
Elizabeth	Clinical Psychologist	Early Intervention in Psychosis	One Year Foundation Course	2019
Alicia	Social Worker and Systemic Family Therapist	Early Intervention in Psychosis	Three Year Course	2021
Jeremy	Consultant Psychiatrist	Early Intervention in Psychosis	Three Year Course	2019
Erin	Consultant Clinical Psychologist	Early Intervention in Psychosis	One Year Course	2021

Interview Schedule

A qualitative interview is described by Smith, Flowers & Larkin as ‘a conversation with a purpose’ (Smith, Flowers & Larkin, 2009, p. 57) that is designed to facilitate participants in discussing their experiences in their own words. To begin the interview the lead researcher checked in with how they were feeling about doing the interview. Practicalities were discussed, such as the time frame for the interview, and informed consent was again obtained verbally. The semi-structured interview schedule can be seen in Appendix 3. The schedule was designed to be open and exploratory whilst simultaneously eliciting the overall experience of integrating OD to NHS psychosis services. The questions were designed to allow for flexibility to

ensure participants felt able to bring the parts of their experience that felt most salient, allowing for the individual voices of clinicians to come through in the data. To elicit data that reflected the meaning participants made of their experiences, the exploratory prompts were used throughout the interviews.

Ethical Considerations

In June 2021 an initial research proposal was submitted to the university by the lead researcher and initial approval was received. Subsequently, full ethical approval for the study was granted by the Salomons Institute for Applied Psychology Ethics Committee in July 2022 (Appendix 4). All participants provided informed consent prior to participating in the study, including partaking in the interview and the interview being audio recorded.

Procedure

After participants expressed their interest in participation via an email to the lead researcher, they were sent the information sheet and consent form. Participants were encouraged to read the information sheet carefully and given seven days to sign and return it. A virtual interview was then scheduled. At the beginning of the interview, participants were given the opportunity to ask any questions they may have had about the research. The semi-structured interview then began gently guided by the interview schedule. The interviews lasted between 50 to 90 minutes. All participants engaged in the interviews without any distress.

Data Analysis

The data analysis was completed using the guidance recommended by Smith, Flowers, & Larkin (2009). Interviews were transcribed by the lead researcher and then read over several times to become familiar with the data and fully immersed

within the participant's world. Initial exploratory notes were then made on individual transcripts. Descriptive, linguistic, and conceptual comments were made, along with the researcher's own interpretations noted on the transcripts to ensure IPA's "double hermeneutic" multi-layered analytic method was adhered to. Experiential comments were grouped together to generate 'Personal Experiential Themes' (PET) for each individual transcript, and at this stage the data shifted further away from being simple and descriptive, towards interpretative. The data set was then taken as a whole, where patterns were identified across the data and related themes were clustered together. This allowed Group Experiential Themes (GET) and their respective subthemes to emerge. Individual transcripts were continuously re-visited to ensure the GETs were representative of the whole data set. Analysis was a continuous and dynamic process, with themes being renamed and reconceptualised or removed from the analysis to allow a broader representation of the data set to emerge. Although the process of IPA is described as a series of steps, it is important to note that the analytic approach is a "dynamic, non-linear style of thinking" (Smith, Flowers, & Larkin, 2009 p. 28) in which the research moved between different steps and ways of thinking about the data. Throughout the process the themes were discussed with the research supervisors. This dynamic process allowed the analysis to become deeper as it progressed, resulting in a data set that is the product of both the participants and the researcher.

Quality Assurance

Throughout the research process the lead researcher kept a reflective research diary, as is recommended by Smith, Flowers, and Larkin (2009). The key purpose of this was to ensure that the research continuously worked both reflexively and reflectively throughout the research process. The lead research had regular supervision with the two project supervisors to support the entire research process

from formation of the research question to analysis and beyond. Supervision allowed for a reflective space to consider the lead researcher's position and how this may have impacted the analytic process. The lead researcher also took part in a bracketing interview with a trainee colleague to further consider their position in relation to the research.

Reflexivity statement

Researcher reflexivity is central to IPA and allows the researcher “a dual perspective of being both inside and outside the research” (Goldspink & Engward, 2019, p. 291). A reflexive position allows the researcher a thoughtful position that considers their own presence within the research (Goldspink & Engward, 2019). It is therefore essential to consider my own position in relation to this IPA research study. I am a Trainee Clinical Psychologist with a critical stance. I believe that the medicalisation of distress obscures the wider context of the individual's suffering, and my values therefore align with a social constructionist approach in relation to psychological distress. This means that I hold certain assumptions. For example, I feel that NHS mental health services could better serve the idiosyncratic needs of clients if they were not centred solely on the medical model. I am passionate about the OD approach and its introduction to NHS mental health services. I am mindful of the challenges associated with creating organisational change within the NHS which I have experienced firsthand when attempting to create systemic change that aligns with the OD approach in the context of acute inpatient services. I hope to continue supporting the integration of OD within the NHS throughout my career.

Results

Following analysis findings were organised into four (GETs) and nine sub-themes (table 2) and are presented below.

Table 2: Overview of themes and subthemes

Group Experiential Themes	Sub-Themes
Recalibration journey	Recalibration from impossible to possible Recalibration from utopia to reality
The redistribution of power	Clinicians' need to hold the expert position The relationship between clients and the expert position
Anxiety and resistance to change	Systemic resistance to change Scepticism of the approach 'Professional rivalry'
Creating the change	Bringing the team alongside Garnering support from those in power

GET 1: Recalibration Journey

Five participants described their experience of integration through the metaphor of a 'journey'. The researcher felt drawn into the metamorphosis of the participants' experiences; seemingly shifting from a sense of 'stuckness' when integration felt unrealistic, to euphoria at the thought of successfully creating change that aligned with OD, to challenges that brought the participants back down to the 'reality' of integration within the existing structure of services.

Recalibration From Impossible to Possible. For Derek, an experienced Consultant Clinical Psychologist, the journey described an initial sense that his 'dream' of bringing OD to services could not be realised:

'I sort of remember feeling like it was almost so far away from the current system that it was, it seemed yeah, like a bit of a pipe dream, almost' (Derek).

There was a sense of disappointment in Derek's tone and language. 'Pipe dream' conveyed a fanciful idea; perhaps OD felt too idealistic to implement within the existing structures of the NHS. This appeared to be disheartening for him early on in his journey of integration and change. However, there seemed to be a shift for him following a series of workshops he attended about the delivery of OD within the NHS:

'Maybe this idea that impossible is just, just in my own mind, you know?' (Derek).

There was a sense that Derek felt inspired by the workshops and there was a fork in the road on his journey; a moment of revelation. There was now a lightness to his tone of voice here, when he reflected on the moment he no longer felt change was 'impossible'.

Similarly, Alicia, an experienced family therapist with a background in social work, also seemed to describe her experience of integration as a journey. She seemed to hold a similar initial position to Derek; this was felt in the similarity of her language to Derek's. She referred to integration as a 'fantasy world':

'When I first heard about open dialogue, to be honest, I thought it was a bit of a fantasy world, you know?... how the hell was it going to be applicable to... inner London?!' (Alicia).

The turning point in Alicia's journey seemed to stem from disillusionment with current practice, when Alicia moved from viewing integration as a 'fantasy' to a possibility born out of frustration:

'I thought there's no way that it's gonna work but I became quite frustrated I suppose with current practice, in terms of treatment as usual, I thought, well, why can I not just try it?' (Alicia)

Recalibration From Utopia to Reality. Three participants experienced a shift from idealistic expectations of what integration of OD would look like, to more realistic expectations of what was possible. For Jeremy, an experienced Consultant Psychiatrist, his journey began with what he described as a 'utopian' vision:

'You become a little bit sort of maybe utopian quite easily, when you've sort of just done the training' (Jeremy).

Jeremy seemed to describe an initial sense of excitement and euphoria in relation to bringing change, but his position shifted as his journey progressed and he became more experienced in attempting to integrate OD and bring change:

'Actually, I think probably more of a, you know, just start where you are kind of approach I think, is good' (Jeremy).

He appeared to let his 'utopian' vision go and took up a position grounded in the reality' of working within existing NHS service structures. Derek also described a similar experience of his journey:

'When I started, I had... hopes or ambitions, that, you know, in a couple of years time, the whole service would be open dialogue... part of this journey... it's been a kind of maybe a kind of a recalibrating of my expectations' (Derek).

For Derek, there is a sense here of ongoing learning and adapting one's expectations of integration as the journey progresses. Alex, a systemic family therapist echoes this sentiment, and reflected on what he had '*learnt along the way*' and the importance of '*being realistic about what you can actually do*' within the existing structures of services.

Theme 2: The Redistribution of Power

This GET documents the changes to the powerful ‘expert position’ that participants experienced when bringing change and integrating OD. These changes in practice were described as having an impact on their colleagues, clients, and themselves.

Clinicians need to hold the expert position. Alicia’s view suggests that the value of holding the ‘expert’ position is intrinsic to the culture of EIS:

‘I think the position of the expert, I think it’s, it is somehow almost, I think it’s quite valued within EI. You’re good at your job if you know your stuff’. (Alicia)

She appears to describe a dominant discourse underlying the value associated with expertise that a competent practitioner is defined by the holding of expert clinical knowledge. This suggests that a sense of confidence and safety in one’s professional abilities is gained by being the expert. Erin’s wondered whether anxiety might underlie the desire for clinicians to remain in positions of power. She seemed to suggest that the redistribution of power that OD brings seemingly moved non-OD trained clinicians into a space of feeling deskilled and vulnerable:

‘I think often when people get anxious or feel inexperienced, they can hold on to a desire to seem knowledgeable, and that’s not necessarily that helpful. Those may be times where power then creeps in when you didn’t mean it to’ (Erin).

This perhaps implies that the OD approach may be experienced as ‘unsafe’ because the containing expert position is removed. There is also a sense here that powerful unconscious processes in relation to power may exist within her service. Derek spoke more directly to unconscious processes in relation to power, and seemingly felt that the change in positions of power may be experienced as ‘threatening’ by some clinicians:

'I think, you know, people who've, either consciously or unconsciously, quite like being the expert in the room ... relinquishing that power is quite a threatening proposition' (Derek)

Erin went on to reflect on how 'power' is felt differently within the context of OD for her. As opposed to power stemming from a professional expert position, power seemed to derive from permission to bring her authentic self to network meetings and connect, simply as human beings:

I found it... quite liberating to be able to be more genuinely yourself, in the room with people... you start to see how powerful that is... everyone is human connecting at the human level is more powerful' (Erin)

The relationship between clients and the expert position. In contrast to the previous theme, some participants reflected upon how the sharing of power seemed to be valued by clients and their families. For Alex, he seemed to witness how powerful it can be to give his client's autonomy pertaining to treatment decisions in the context of the OD approach:

'Service users say they feel that it's [OD] different 'cause they've been genuinely heard... It's not just coming in and being told what's going to happen to you, it's like, what do you want to happen for you?' (Alex)

Similarly For Erin, both she and her clients seemingly welcomed the genuine control and collaboration through this different way of working. There seemed to be a sense of irritability in her tone, perhaps almost mocking, when discussing treatment as usual, and a lightness to her tone when discussing OD. This was understood as reflecting her frustration with current practice, and the welcome changes that OD brings to the service in her view:

'You might still have covered risk, or medication... things like that come up and get covered, but not from a place of 'I'm gonna run down my list of questions that you need to answer'[slight irritable/ mocking tone of voice] like the person feels like they've steered it, but also that we're all in it together [slower, lighter tone of voice]'
(Erin)

Interestingly, Erin described being able to work effectively with clients in EIS but in a less prescriptive and traditional 'expert' way. She describes a different dynamic in which she brings her expertise from a position that is alongside the client, which was understood to be important to her. However, there was contradiction within Erin's experiences:

'There were a lot of people who come who just want, they just want a solution and an answer... they're hoping that you almost have the power to make the changes that they think the family member needs' (Erin)

Here, she described experiences in which clients seemingly came to services seeking expertise from a clinician to contain distress and find solutions. She seemed to feel conflicted about this; perhaps wanting to redistribute power to clients but being pulled into traditional power dynamics with distressed individuals seeking certainty.

Theme 3: Anxiety and Resistance to Change

This GET explores the sense of resistance and anxiety to change that all participants experienced. Anxiety and resistance manifested in different forms and at different levels of the organisation, from systemic to individual. Anxiety and resistance came hand in hand with a reciprocal relationship in some instances, and in some instances resistance appeared to occur without anxiety, and vice versa.

Systemic Resistance to Change. All participants described a sense of resistance to change that permeated the wider NHS system. Derek reflected on his long career that he has dedicated to integrating OD to services:

“Where you've got an approach like Open Dialogue... it's about the way services are organized and fundamentally, it's about the culture of the organization. It's just a much bigger project and so there is just a lot of inertia and resistance to change within the system” (Derek).

There appeared to be an underlying sense of pessimism here that the researcher sensed; perhaps, for Derek, it felt as though the system was not capable of change on a large scale. It felt as though Derek understood this to be underlying the resistance he encountered. Derek's tone and the use of the word like 'inertia' were felt as powerful and epitomise the undertone of pessimism, and perhaps hopeless, in relation to integration of OD. This sense of resistance and challenge within the wider system was echoed by Alicia:

“We are challenging how an EI service normally operates in the U.K... There is a belief of 'this is the way, and this is the only way'... the NHS is very, very committed or invested in treatment as” (Alicia).

Alicia's understanding of the resistance seems to be related to a reluctant to relinquish existing ways of working within services. Elizabeth is a Clinical Psychologist that has moved service several times when she felt she reached a “stalemate” in relation to bringing change and integrating OD. She reflected on one particularly difficult experience in her current service where OD came “under threat”:

'It was under threat... people were saying like, 'oh, like, let's, why don't we just pause this for a while?'... I mean, there was lots of resistance. And I really didn't want

it to get lost again for me. I was really, really worried about that [shakes head]' (Elizabeth).

There is a sense that perhaps Elizabeth encountered resistance because OD was not a priority for the service, and the anxiety this was bringing up for Elizabeth her was palpable.

Suspicion of the approach. At the level of non-OD trained clinicians, resistance and anxiety appeared to manifest as a sense of suspicion towards the OD approach. Two participants (Jeremy and Elizabeth) used the metaphor of a “cult” and employed language that held religious connotations to describe the OD approach:

'I've heard people say, you know, 'it's very Evangelical, it's a bit like a cult, open dialogue' (Elizabeth).

The profundity of their words made the researcher wondered if OD-trained clinicians may be viewed as ‘converted’ to the model; in turn creating a dichotomy between those already converted and those still to be converted by the ‘cult-ish’ movement.

A particularly profound statement was made by Alicia during her interview when reflecting upon her experiences of suspicion and resistance to the integration of OD:

'I think if the fear was less it would be welcomed. You know, this isn't communism! [laughs and throws hands in the air]' (Alicia).

Alicia spoke in an animated and expressive way throughout her interview and became particularly animated here. This was understood as a passionate defence of the OD approach; perhaps she was frustrated by the continuous resistance she has met throughout her many years of experience to an approach she believes in. Her use of hyperbole when comparing OD to the extreme political ideology of communism seemed to be for shock value. Her delivery of the statement was seemingly intended

to be simultaneously humorous and conveying her anger towards those that feel suspicious of OD.

Julie experienced suspicion towards the approach from non-OD trained clinicians differently. This seemed to be in the form of questions pertaining to the evidence base:

'There's a strong, you know, we have been sort of challenged in terms of 'what's the evidence base?... I think there's that sort of tension around for sure' (Julie).

Julie said this in a sarcastic tone that seemed to convey annoyance towards the 'tension' created by those that are suspicious of the approach; she went on to say: *'The work is not robust enough for our [the NHS] standards apparently [rolls eyes]... we have to innovate, we have to create evidence! You know what I mean? [laughs] it's not going to just happen!'*

It is possible an underlying anxiety in non-OD trained clinicians drove suspicion towards the model for multiple participants. However, Alex seemed to hold a more empathetic view for his team, attributing the suspicion of OD to an understandable mistrust for a relatively unknown approach. His tone was soft and he appeared thoughtful:

'I think people felt anxious, like with the team not knowing open dialogue or what we're trying to do there's a distrust of what they don't know, it might have felt a bit of an unsettling space to be in' (Alex).

In contrast to Alex's sympathetic position, Alicia reflected upon an experience with a psychiatrist in her team. She seemed dismissive of their overt display of resistance, and could not understand what prompted a 'bananas' reaction:

'The psychiatrist in my team, one of them, went absolutely bananas! Saying that was such an unsafe thing to do, unsafe practice. It's not to be trusted, it was something that has no research whatsoever'.

As the only psychiatrist among the participants, Jeremy was a unique voice amongst the participants. He reflected on why he felt medics may be suspicious of OD. He seemingly spoke from a position of duality; holding compassion for his fellow medics but also believing in the power of OD and wanting to bring it to services:

'The feeling and of the emotion side of things [OD] was quite far and away for somebody who'd been trained in Biological Psychiatry... so I understand medics may be afraid of something that asks you to feel, but to me it sort of felt a little bit like coming home [closes eyes], like a warm hug' (Jeremy)

Professional Rivalry. The participants seemed to feel their non-OD trained colleagues' resistance to adopting the approach may be due to a vested interest in one's own professional models. Julie seemed to perceive that her colleagues' resistance to OD stemmed from a need to 'defend' their own preferred models. Her use of the word 'rivalry' held powerful connotations of battle, a fight for the superior model. Perhaps there is a sense that one's professional background and training means that they want to prioritise their own way of working with and understanding distress. It was as though multiple models cannot co-exist within one service:

'For some people, it might be sort of professional rivalry and people sort of keeping, you know, they've got their own investment in their own models... and there's a want to sort of defend that' (Julie)

Julie went on to reflect on the impact of resistance on her. One could argue that Julie feels a heavy sense of responsibility for the acceptance of OD, a model she deeply cares about, within the team:

'It does bring an anxiety, you know, for people that are cynical about the meetings or critical of them... I certainly can feel 'Whoa, there's a lot at stake here' (Julie)

Julie added that she feels a sense of 'imposter syndrome' when others question the model, and went on to say: *'it makes me question like, is this what we should be doing?'*

For some participants, there appeared to be a sense that their colleagues felt the integration of OD would replace existing models. There appears to be a binary 'either/or' narrative as opposed to a 'both/and' point of view. Five participants spoke about a sense of professional rivalry in relation to their psychiatry colleagues. For Alicia, there was a sense that psychiatrists may experience OD as invalidating; Alicia seemed to believe that the psychiatrist in her team felt threatened by a 'new' model that opposes the dominant medical model:

'Psychiatrists are more old school, they have built up their careers working in a very, very particular way... Open Dialogue could be heard as invalidating, you know. They have a life-long practice, so I'm thinking that it's a sense of a fear of the new' (Alicia).

Jeremy's view seemed to align with Alicia's, commenting that psychiatrists may be particularly resistant to OD:

'Medics I think they are... they're harder to convince [laughs] that an attitude change would be helpful' (Jeremy)

Derek also shared his view on a psychiatrist in his team feeling the need to defend the medical paradigm in which they work. Derek's sense making of this experience seemed to align with Alicia's; perhaps psychiatrists felt invalidated by the introduction of OD:

'I think people come away with the idea is, we're telling them they're not doing their job well enough... I remember, having a conversation with one of our consultant psychiatrists, who basically said, 'Look, I'm a good psychiatrist... I'm sure I can improve, but I don't need to kind of completely change my approach' (Derek)

Theme 4: Creating The Change

All participants shared a strong desire to effect change and develop OD within their respective services. This GET highlights how the participants used a range of methods that they felt were helpful to support the integration of OD to their services in the face of these challenges. It appeared that participants wanted to support their colleagues to better understand the model in response to the anxieties and resistance to integration of OD that they faced.

Bringing the Team Alongside. The participants seemed to share a sense of wanting to bring non-OD trained clinicians into the process of integration and change. The motivation for this appeared to be to manage anxieties within the team and foster a sense of safety amid change. Julie spoke about the importance of 'warming the context'. Julie seemed thoughtful, and it seemed important to her to ensure that her colleagues for comfortable:

'We, sort of hoped ... that we could sort of warm the context, if you like, to bring people in and for people to be interested in more open dialogue and help them to feel safe with it' (Julie)

Julie's use of language such as 'bringing people in' and ensuring her colleagues felt safe conveyed a sense of gentle-ness and care in her approach. This sense of gently 'bringing in' non-OD trained colleagues in on change was shared by Derek. He spoke

directly to some specific techniques that he seemingly used to successfully ‘warm the context’ within his service:

‘I had a couple of sort of CPD sessions that I did about the approach and introducing people to the ideas.... There was a lot of interest, you know, some kind of excitement about this’ (Derek)

Derek seemingly aimed to generate a context to allow change to take place in a comfortable space. Similarly, Jeremy also spoke about how he supported his colleagues to feel comfortable with the integration of OD:

‘We did do a number of short trainings, like day or half day trainings, with the team, just telling them what it was all about... so there was a certain amount of effort to help the team, understand what was what it was, and sort of create some interest’ (Jeremy)

To make the integration of OD a shared endeavour with her non-OD trained colleagues, Erin regularly brought these clinicians into network meetings:

‘Because we actually have someone from the team there, it's about more of a shared, that actually felt a bit more integrated in their team and it felt less threatening’ (Erin).

This seemingly supported the integration of OD into the wider team. There is a sense here that supporting non-OD trained clinicians to experience OD first-hand is essential to allow the sense of threat that may be triggered by integration to subside.

Garnering Support From Those in Power. All 7 participants discussed the importance of gaining support for integration and change of the approach from those in and those in positions of power. Elizabeth spoke about her challenging experiences of often feeling “stuck” with integration. To mitigate her stuckness, she seemed to search for those that are sympathetic to change in powerful positions and made the powerful statement: ‘it’s all about allies’. There was a sense that Elizabeth found the

process of integration draining, which was evident in her tone, and finding allies for her ‘gave me a bit of strength’.

Julie also reflects upon the importance of having ‘allies’ in positions of power. There was a sense that Julie took pride in this, and that this was a positive turning point with respect to integration and change:

‘We had garnered really good support... were open to trying something different... in sort of more senior management and psychological therapies management.’ (Julie).

Jeremy reflected on an initial feeling of being ‘out in the cold’, which implied a sense of rejection from management initially. This seemingly ‘switched’ once management were onside and this allowed OD to ‘bed in’ to the service:

‘Latterly, it feels like it's sort of bedding in a little bit... because of management support. It switched from that kind of initial sense that we were a little bit out in the cold’ (Jeremy)

Discussion

This study aimed to explore the experiences of OD-trained clinicians attempting to bring organisational change to NHS EIS to integrate OD within the existing structures of NHS EID. Participants gave thoughtful and reflective accounts of what this experience is like, along with the associated challenges and successes throughout their ‘journey’.

All participants seemingly experienced then integration of OD as a journey; one that is ever-changing and non-linear. For some participants, aligning the contrasting paradigms of the medical model and OD felt ‘impossible’ at the start of the journey. For OD to successfully embed within existing services in a meaningful way major changes would need to take place to the organisational structure and culture of services, and non-OD trained clinicians would need to undergo a ‘transformational

learning process' (Wates et al., 2022, p. 789). Indeed, some of the participants seemed to come to this realisation along the way; shifting from visions of "utopia" and hoping to transform services in their entirety, to realisation this may not be possible within the current system. Such dilemmas seemingly led participants to adapt their approach to change, and their expectations of change, as opposed to attempting to integrate OD in its purest form, which is a finding resonate with the literature (Freeman et al., 2019; Cotes et al., 2023).

The findings of this research support Tribe et al. (2019), who found that resistance to change and embracing OD is common among non-OD trained clinicians. Specifically, participants experienced resistance from colleagues to reorientate themselves away from positions of power, such as the expert position. Some participants speculated that this could be anxiety-driven; non-OD clinicians seemingly felt deskilled and perhaps vulnerable in the face of change to familiar ways of working, particularly the perceived loss of the expert position. Applying Mason's (2022) concept of 'safe uncertainty', it could be argued that the familiar expert position provides clinicians with a containing sense of 'safe certainty' (Mason, 2022). This desire to hold on to expert position may uphold the reluctance to move towards the organisational changes and changes in practice that OD calls for. The OD approach was perceived as an 'uncertain' way of working that seemingly made non-OD trained clinicians feel 'suspicious', and perhaps distrustful, of the model, which appeared to inhibit the adoption of OD. If OD-trained clinicians were able to empower staff to move to positions of "safe uncertainty", this could support staff in shifting to positions of "safe uncertainty" and away from existing authoritarian-style practices (Mason, 2022). This could, in turn, made the integration of OD feel less threatening and support change initiatives.

This research also contributes to the theoretical literature on organisational change. Applying the TMM, after the completion of OD training the clinicians began practicing in services in which teams may have been in the “pre-contemplation” phase in which organisation members were yet to consider changing existing ways of working. This could somewhat explain why some participants came to the realisation that change on a larger, organisational scale did not feel possible.

A salient finding of this study was that the participants met anxiety and resistance to change that manifested in different forms. The TMM posits that imposing change on those who are not ready will drive up resistance, and this is the most common reason for change initiatives to fail within organisations. Indeed, there was a sense of non-OD trained clinicians, feeling ‘threatened’ and ‘suspicious’ of OD, which prevented them from progressing through the stages of change. In some instances, the rejection of OD seemed to be related to worries pertaining to a protectiveness of one’s own professional models, which left little room for such existing ways of working and OD to co-exist.

The TMM, although situated in the theoretical literature on organisational change, is complemented by the idea of ‘warming the context’ that is rooted in systemic theory which seems particularly relevant to findings of this study. ‘Warming the context’ refers to preparing an environment for important conversations about change and difference within a context that feels safe and familiar (Burnham, 2018). The perceived risk associated with moving away from current practice may prevent clinicians from embracing change and adopting new ways of working, which may persist even when clinicians hold a desire to change (Fotaki & Hyde, 2014; Edmonson et al., 2016); perhaps such clinicians are in the “contemplation” phase and must be shown that the benefits of change outweigh the costs (Prochaska et al., 2002).

In the face of resistance, participants were able to mitigate some of the negative effects of bringing change within the team by using various with some success, including CPD sessions and in-house workshops for MDTs. The success that these interventions had suggests that participants were able to support teams to progress from early stages of change, such as “pre-contemplation”, to “contemplation” or even “preparation”. Some participants spoke about their successes with introducing NMs to their teams, which may suggest that some teams were able to progress through to the “action” or “maintenance” phases of the model. This suggests that the interventions the participants used effectively reduced the resistance and anxiety driven by change. This is congruent with current literature, which highlights the importance of bringing team members alongside and creating space to hear the voices of those that may be feel concerned or threatened by the change that OD brings to service provision to ready teams for change (Tribe et al., 2019). The action participants took complements the existing literature, which has highlighted the importance of bolstering the implementation of OD through multiple different strategies including workshops and OD champions. This can support services to shift the delivery of care and overall culture in line with OD (Cotes et al., 2023), which resonates with the experiences of the participants.

The participants highlighted the importance of finding “allies” and garnering support from senior management to bringing about organisational change and embed OD within their respective services. Applying the TMM, management support can help not only with beginning “conscious raising” within teams that readies the context for change but can also support the long-term goal of integration at the final “maintenance” stage of the model. However, it is important to strike a balance and not to impose the “action” stage in a top-down way, or this can drive resistance to change

within the organisation and make the integration of OD more challenging. The participants seemed mindful of this, which was evident in their genuine desire to “bring the team alongside” in relation to change.

Clinical Implications

Perhaps the most salient finding from this study is that when OD-trained clinicians bring change and the integrate of OD to services, readying the context of the organisation for change is deeply important. Seemingly, the most useful ways to go about creating change were employing “conscious raising initiatives” (CPD sessions, workshops, inviting team members to NM) that may accelerate employees through to the “contemplation”, “preparation” or “action” stages of change. This is congruent with existing literature, which suggests that teaching clinicians the core principles of the approach can foster acceptance of change and allow for successful integration (Cotes et al., 2023; Kinane et al., 2022). This suggests that it is important for OD-trained clinicians, NHS Trusts, and service management to employ these types of strategies.

Limitations

A limitation to this research may be that the focus was on change and integration of OD within the context of NHS psychosis services, specifically EIS. The lead researcher did not limit the inclusion criteria to clinicians from EIS, however, all participants practiced within this type of service by coincidence. This may mean that the results are not directly applicable to the integration of OD within different service types, limiting the generalizability of the findings. This may mean that the results are not so relevant to the experience of clinicians integrating the approach to other service types (e.g. crisis services or community mental health).

Implications For Future Research

The present study contributes to the qualitative literature in relation to the experience of integrating OD to NHS EIS and the theoretical literature on organisational change. Future research could build upon these findings and explore the experience of the integration of OD and change from the perspective of non-OD trained clinicians. This could help to further elucidate some of the challenges that have been brought to light in this study, such as anxiety and resistance to change. Understanding this experience could help to further develop our understanding of what is required in order to create further organisational change that fosters adoption of OD can take place.

Conclusions

This study illustrated the experience of clinicians attempting to create organisational change to foster the adoption of OD within NHS EIS. A total of 4 themes and 9 subthemes were derived from the data. The participants described their experience as a complex, ever-changing, and non-linear ‘journey’. This research highlighted some of the challenges associated with integration, such as anxiety and resistance to change that seemingly manifested in different forms. The role of power within conventional EIS was also highlighted in relation to the wider service structures, individual clinicians, and senior management, and how this may help or hinder the processes of change and integration. This study contributed to a gap in the theoretical literature on organisational change, and elucidated why clinicians may meet resistance and anxiety when integrating OD, and why some of these negative effects can be mitigated. For example, CPD sessions, supporting clinicians to get involved with NMs, and educational workshops. Clinical implications include potentially useful methods of facilitating organisational change based on the

participants experiences. To continue support the integration of OD in the U.K., useful future research may explore the experience of the integration of OD from non-OD trained clinicians.

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<https://www.ucl.ac.uk/pals/research/clinical-educational-and-health-psychology/research-groups/oddesi/oddesi-trial>

Section C: Appendices and Support Materials

Appendix A: Critical appraisal skills programme (CASP) criteria for qualitative research studies.

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?

Section B: What are the results?

7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?

Section C: Will the results help locally?

10. How valuable is the research?

Appendix B: Consent form for participants



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

CONSENT FORM

Title of Project: Clinicians' experience of integrating the Open Dialogue approach to NHS practice
 Name of Researcher: Aimee Morgan

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 agree to my interview being audio-recorded.
- 4. I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings.
- 5. I agree for my anonymous data to be used in further research studies.
- 6. I agree to take part in the above study.

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

Appendix C: Information Sheet for Participants.



Salomons Institute for
Applied Psychology

One Meadow Road, Tunbridge Wells,
Kent TN1 2YG

www.canterbury.ac.uk/appliedpsychology

Information about the research

Clinicians' experience of integrating Open Dialogue to NHS practice

Hello. My name is Aimee 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?

The purpose of this study is to gain a deeper understanding of what it is like for clinicians to integrate their training in the Open Dialogue approach to their NHS practice within a mental health service for psychosis. It is hoped that this research project will be educational, and may contribute to our understanding of the successes and challenges that exist when integrating this approach to clinical practice.

Why have I been invited?

You have been invited to practice in this study as you have completed the one year or three year course in Open Dialogue Training. Approximately 8-10 participants will be recruited to the study.

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?

You will be asked to take part in one single sixty-minute interview with me over Zoom. You will not need to do anything else after participating in the online interview. The interview will consist of open questions that focus on the research question, whilst allowing room for you to bring your individual experience with regard to integrating OD into your practice. The interview will be audio recorded so that the interviewer can complete a written transcript of the interview that will form part of the data for the project. The transcript will be fully anonymised, meaning that all identifiable data will be removed from the transcript (for example, your name and/or place of work). 8-10 participants that have completed OD training and practice within NHS psychosis services post-training will be recruited. The interviews will then be

analysed using Interpretative Phenomenological Analysis (IPA), a method of analysis that seeks to understand how the participant understands their personal experiences on a deep and meaningful level.

What will I be asked to do?

You will be required to participate in one single 60-minute interview via zoom. There will then be an optional debrief at the end of the interview.

What are the possible disadvantages and risks of taking part?

There is a small risk that you may find it upsetting to discuss your experiences in relation to your clinical work. This could bring up difficult emotions and/or prompt you to reflect upon challenging experiences faced in your clinical role.

What are the possible benefits of taking part?

Key benefits of this project include contributing to our understanding of integrating OD to NHS mental health services for psychosis, feeling valued and having contributed to recommendations that may develop our understanding of how best to integrate OD to NHS psychosis services.

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.

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

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

You can withdraw before or during the interview at any time without justification. After your interview, you can withdraw your data at any time up until December 2022 and you will no longer be contacted in relation to the project from April 2023 as this is the completion point of the finalised project. You can withdraw by contacting the lead researcher by email or telephone. This has been set as the deadline as the data analysis and first draft of the report will be complete at this stage and it will not be possible to remove individual participant data once it has been assimilated.

Concerns and Complaints

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 [Aimee] 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?

Your interview transcript will form the basis for data in this study. The lead researcher (I, Aimee Morgan) will have access to your personal data and will anonymise the written transcripts. Nobody other than the lead researcher will have access to personal identifiable data.

The names and code number/pseudonyms of participants will be stored in locked cabinet that is not kept in the same location as the transcripts. The transcripts and other materials for the project will refer only to code numbers/pseudonyms. Interviews will be recorded on a digital voice recorder and transferred immediately onto an encrypted, password-protected memory stick. Following transcription, the original recording will be permanently deleted. Typed transcripts will be stored on this memory stick.

The transcripts of the interviews will be anonymised during the process of transcription. Direct quotations will be changed where required to uphold confidentiality and protect the identity of participants. For example, name of place of work, place that they live, any other person mentioned, will be anonymised to prevent identification of participants.

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?

Participants will be provided with a version of the findings of the study. This will be a written summary of the key findings via email. There is a possibility that in the future this research may be published, and anonymised extracts from the written transcript may be included in the published article to support themes derived from the data.

Who is sponsoring and funding the research?

Canterbury Christ Church University only.

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 Salomons 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 leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me [Aimee] and leave a contact number so that I can get back to you.

Appendix D: Interview Schedule

- 1) What service are you currently working in and what is your job role?
- 2) How long ago was your Open Dialogue training?
- 3) Did you do one year or three year training course?
- 4) What interested you about the Open Dialogue approach?
- 5) What has your experience been of integrating your training to your practice?
- 6) What challenges or struggles, if any, have you come across when integrating your training in Open Dialogue to your practice?
- 7) What successes, if any, have you had when integrating your Open Dialogue training to your practice?
- 8) What have you found enjoyable or rewarding, if at all, about integrating your new way of working?
- 9) What has your experience been of integrating your Open Dialogue training to a psychosis service?
- 10) Is there anything else that you would like to add to this interview with regard to integrating your OD training to your clinical practice?

Prompts:

- Could you tell me more about that?
- Why is that?
- What was that like for you?
- What sense did you make of that?
- How did you manage that experience?
- Could you go into a bit more detail about that experience?
- How did that affect/impact you?

Appendix E: University ethical approval

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Appendix F: Example coded transcript with exploratory notes and experiential statements.

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Appendix G: Example organising Exploratory notes into Experiential Statements.

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**Appendix H: Example organisation of Experiential Statements into Personal
Experiential Themes**

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**Appendix I: Example Organisation of Personal Experiential Themes into Group
Experiential Themes**

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Appendix J: Abridged Bracketing Interview

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Appendix K: Abridged Research Diary

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Appendix L: End of study letter to Salomons ethics panel

Dear Salomons Ethics panel,

Project Title: An Interpretative Phenomenological Analysis of the experience of clinicians integrating Open Dialogue to NHS psychosis services

Thank you for giving me the opportunity to carry out this research project for my doctoral thesis. Following ethical approval in July 2022, the project has now been completed. Please find this letter as confirmation of this.

There is growing interest in bringing Open Dialogue to NHS mental health services, particularly NHS psychosis services. Clinicians that have been trained in OD experienced the training as transformative, but little is known about the experience of the clinicians attempting to integrate the approach. This research project endeavoured to address this gap in the literature.

A total of seven mental health professionals that work within NHS psychosis services were interviewed using Interpretative Phenomenological Analysis. The four major themes that emerged from the data are summarised below.

Recalibration Journey

This theme brought to light a sense of a ‘journey’ with respect to the integration of OD to EIS and summarised the continuous process of recalibration that participants experienced. The participants’ expectations of the degree of integration that was possible within their services continuously changed over time and required recalibration at various points throughout their journey.

The Redistribution of Power

This theme explored the changes to the ‘expert position’ that were created through the integration of OD to EIS. The participants’ experiences highlight the different relationships that are held in relation to the expert position, from clinicians within EIS to clients of EIS. Significant value appears to be placed on the expert position by clinicians and a reluctance to move away from this valued position of power was seemingly disruptive to the integration of OD. Contrastingly, clients appeared to value this redistribution of power, which created an increased sense of autonomy and empowerment.

Anxiety and resistance to change

This GET explores the sense of resistance and anxiety to change that all participants experienced throughout the integration process. Anxiety and resistance manifested in different forms and at different levels of the organisation, from systemic to individual. There was a sense that the relationship between anxiety and resistance at both levels was complex. Anxiety and resistance came hand in hand with a reciprocal relationship in some instances, and in some instances resistance appeared to occur without anxiety, and vice versa. The first subtheme explores anxiety and resistance to change at an organisational level. The second subtheme explores it at the individual level of the participants non-OD trained colleagues.

Creating the change

All participants shared a strong desire to effect change and develop OD within their EIS. The previous GETs have highlighted the overall experience of integration and some of the challenges that integration of a new approach can bring, such as anxiety, resistance, and complex dynamics and processes. This GET is the final part of the story, which highlights how the participants used a range of methods to support the integration of OD to their services in the face of these challenges. It appeared that participants wanted to support their colleagues to better understand the model in response to the anxieties and resistance to integration of OD that they faced.

Best wishes,

Aimee Morgan

Trainee Clinical Psychologist

Appendix M: End of research summary letter to participants

Dear participants,

Project Title: An Interpretative Phenomenological Analysis of the experience of clinicians integrating Open Dialogue to NHS psychosis services

I would like to sincerely thank you participating in my research and sharing your experiences with me. Without you, this project would not have been possible.

A total of seven mental health professionals that work within NHS psychosis services were interviewed using Interpretative Phenomenological Analysis. The four major themes that emerged from the data are summarised below.

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This theme brought to light a sense of a ‘journey’ with respect to the integration of OD to EIS and summarised the continuous process of recalibration that participants experienced. The participants’ expectations of the degree of integration that was possible within their services continuously changed over time and required recalibration at various points throughout their journey.

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Best wishes,

Aimee Morgan

Trainee Clinical Psychologist

**Appendix N: Journal submission information for manuscripts to the
'Community Mental Health Journal'**

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