SPIRITUAL UNDERSTANDINGS OF PSYCHOSIS: THE PERSPECTIVES OF SPIRITUAL CARE STAFF

by

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A thesis submitted to the University of Birmingham for the degree of DOCTOR OF CLINICAL PSYCHOLOGY

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August 2022

Thesis Overview

This thesis is submitted by Reham Al Taher in partial fulfilment for the degree of Doctor in Clinical Psychology (DClinPsy) at the University of Birmingham. It contains three chapters.

Chapter one of the thesis comprises a literature review: a meta-ethnography exploring personal accounts of the facilitators and barriers to seeking help for First-Episode Psychosis (FEP). The process of the meta-ethnography consisted of extracting, appraising, and synthesizing a total of 15 qualitative and mixed-method empirical studies. The second chapter is a qualitative study using Interpretive Phenomenological Analysis (IPA) to explore how spiritual care staff make sense of experiences otherwise termed as “psychosis”. The third and final chapter presents a “press release” of both chapter one and two, outlining its main findings in a manner that is suitable and appropriate for public dissemination.

Acknowledgements

No man is an island and this wouldn't have been possible without so many people's support, encouragement, and guidance. I would like to first thank Dr. Andy Fox –I cannot thank you enough for choosing to be my research supervisor and for taking an interest in this topic. You have been nothing but exceptional. To Carol Wilson, this project would not have gotten off the ground if it wasn't for all of your help, and I always enjoyed our conversations together about spiritual metaphysics. I would like to also express my gratitude to the participants who volunteered to take part in this research project – each and every one of you had so much passion and interest and it gave me the fuel I needed from the beginning to the end.

I would like to thank Dr. Shazma Thabusom and Dr. Nick Zygouris for allowing me to pick your brain at the beginning when I was thinking about exploring spirituality and psychosis. You both not only encouraged me to speak to the University about turning this topic into a research project, but also let me know you believed this is worth exploring and that I was capable of doing it.

To Dr. Michelle Fisher – you were a constant figure of strength over the past three years. From the day of the doctoral interview to now you have always made me feel emotionally safe and I'm forever grateful for that. To the University of Birmingham, thank you for accepting me onto your doctoral programme – it has been metamorphosizing (and that's putting it lightly!)

To my trainee family – being around you felt like having a home away from home. In particular I want to thank Simone, Emily, and Nikita –I've lost track of the amount of times we went through similar experiences, experiences so difficult to articulate that can only be understood if you went through it. Not only did we have shared experiences, but our bond was also filled with support, warmth, and cheerleading each other the past 3 years.

To Mama, Baba, Khaled, Ola, Hania, Saif, and Lara – I wouldn't be me without you. I love you and need you forever and I look forward to the day we're all together again. To Omar, Amanda, Barbara, and Sheila – you have always believed that I could do this and could get through it. Your friendship means everything to me. And finally to the pets I love and to the pets I have lost – Cookie, Panda, Kia, Cappuccino, Bey, Louis, Maxine, and Chiquitita – you made my heart whole and loved me unconditionally. We will see each other again. On the day we reunite we will walk paw in hand to cross over the "Rainbow Bridge" together, and we will "cling together in joyous reunion, never to be parted again."

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Chapter I. Literature Review

EXPLORING PERSONAL ACCOUNTS OF THE FACILITAORS AND BARRIERS TO SEEKING HELP FOR FIRST EPISODE PSYCHOSIS (FEP): A META-ETHNOGRAPHY

Abstract

Background: First-Episode Psychosis (FEP) can occur in several ways, making it difficult to detect by services, families, and service-users themselves. Along with services focusing on early detection, which includes finding facilitators and barriers to seeking help for FEP, there has been growing qualitative research on help-seeking for FEP from those with lived experiences.

Aim: This meta-ethnography aimed to synthesize the findings of qualitative studies that explored personal accounts of the facilitators and barriers to seeking help for FEP.

Methodology: 15 primary articles were identified through eight electronic databases and reference checking. These papers were assessed for methodological quality using two qualitative checklists (American Psychological Association, 2018; NICE, 2012). These articles were analyzed following the guidance of Noblit and Hare's (1988) seven-phase methodology.

Results: The synthesis suggested a chronological process; during FEP's early emergence, most did not seek help, but normalized or contextualized experiences to other psychosocial stressors. As FEP intensified, feelings of uncertainty grew about their initial interpretation, which led to participants generating explanatory frameworks about these experiences. Frameworks either led to or delayed help. Helpful involvement from significant others and services led to help-seeking, while less helpful involvement delayed it. If effective help was still not sought, most experienced a “tipping point” which led to urgent help from services. Facilitators and barriers were also affected by individual, gender, and ethnic differences.

Conclusions: FEP and help-seeking appears to be a process that is affected by and related to one’s intertwining intra-and- interpersonal, cultural, individual, and systemic roles.

1. Introduction

Psychosis refers to experiences of hearing voices, “odd” beliefs, difficulty maintaining cognizance, and exhibiting limited reality-testing behaviors (Arciniegas, 2015; American Psychiatric Association, 2013; World Health Organization [WHO], 1992). It has been demonstrated as having a significant impact on a person’s psychiatric, neurodevelopmental, and medical condition (s), thereby becoming an important target for services to facilitate effective assessment, intervention, and care (Arciniegas, 2015). Meta-analytic studies and other research also show consistent associations between duration of untreated psychosis (DUP) and poorer management of these experiences (Penttilä et al., 2014; Ruiz-Veguilla et al., 2012; Wong et al., 2020). Moreover, mental health difficulties such as psychosis may be both the cause and effect of social exclusion (Killaspy et al., 2013). This not only lessens opportunities for individuals to participate in key areas of economic, cultural, and social experiences, but is also associated with poorer clinical and functional outcomes (Anderson et al., 2020). Therefore, timely help-seeking to appropriate services is crucial.

1.1. What is First-Episode Psychosis (FEP)?

A First-Episode Psychosis (FEP) refers to the time a person first has psychotic experiences (Bromely et al., 2015). FEP can occur in a variety of ways and across diagnostic categories, making it difficult to ascertain and provide help for, especially since it is not typically diagnosed when a person first presents at a service with psychotic-like features (Bromely et al., 2015; Rae et al., 2020). As such, there has been considerable debate about the usefulness and validity in how psychosis has been a) conceptualized in the literature as a diagnostic category and b) theorized as a biologically-based illness (Cooke, 2020). For example, there appears to be a relationship between psychosis and trauma and strong correlations of childhood sexual abuse and onset of psychosis (Bebbington et al., 2011; Mueser et al., 2010; Read & Larkin, 2008; Stanton et al., 2020), which can result in negative perceptions of the self, low mood, paranoia, anxiety, and increased sensitivity to stress – all of which can also appear in psychotic-like experiences (Schäfer & Fisher, 2011; Stanton et al., 2020).

Current conceptualizations of FEP identify three phases (Fusar-Poli et al., 2017), with a variation in the duration of each phase depending on the person and their circumstances (Chen et al., 2019). The first phase refers to a period when a person exhibits subtle changes, such as difficulties in concentration, motivation, mood, anxiety, withdrawal, and having "odd" beliefs (Bromely et al., 2015). Detecting psychosis at this stage tends to be difficult (by services, the person's family, and the person themselves) (Fusar-Poli et al., 2021). The second phase includes experiences such as hallucinations (e.g., hearing voices), confusion, delusions, and significant distress; this can lead to some family members noticing changes and possibly considering help-seeking (Bird et al., 2010). Finally, the third phase refers to the period when the person receives help, which often consists of psychiatric and/or medical treatment from services; it is during this phase that many recover from FEP, with early detection increasing the chances of a person making a full recovery, but some do recover spontaneously, as well (Huxley et al., 2021; Rae at al., 2020).

1.1.1. Challenges detecting FEP in the western world

Because FEP can initially go undetected by services, this increases the risk for DUP and its associated consequences (Hansen et al., 2017). As such, services (mostly in the western part of the world) have increased their focus on early detection for psychosis over the past several years, with interventions being aimed to reduce DUP and provide specialized interventions and treatment for FEP (Albert & Weibell, 2019; Correll et al., 2018). Their focus also includes finding detectable characteristics, facilitators, and barriers to seeking help; help-seeking can be generally defined as "communication with other people to obtain help in terms of advice, information, treatment and general support in response to a problem or distressing experience" (Rickwood et al., 2005).

Cairns and colleagues (2014) found that help-seeking tends to occur when there is a presence of voice-hearing, mood disturbances, and an overall decline in the person's wellbeing, including self-harm. Further, in a latent class analysis on 568 practices in the UK, Chen and colleagues (2019) found that for FEP most reported experiences were mood-related, "neurotic," and/or physical complaints, followed by cognitive and behavioral changes. The study also reported the median age for receiving a diagnosis of a psychotic disorder to be 30 years old, with more males diagnosed than females, and that the median time of receiving a diagnosis was 2-2.5 years from the person first entering the service. Whilst these studies have been helpful in the delivering and planning of service outcomes, it has been criticized for overly-focusing on the roles of healthcare providers and services; research has recommended to include other perspectives, namely from the service-users themselves (Albert & Weibell, 2019; Cairns et al., 2014).

1.1.2. Increasing our understanding of help-seeking for FEP from different perspectives

Meta-analytic, quantitative studies, and qualitative studies have developed our knowledge of FEP from different perspectives. A systematic review on qualitative, quantitative, and mixed-methods research studies found perceived stigma within individuals with FEP and their families as one potential factor for delays in help-seeking (Gronholm et al., 2017). Further, meta-ethnographies on family perspectives of pathways to care for FEP found stigma, lack of knowledge on psychotic-like experiences, and a tendency to normalize FEP play a role in preventing help-seeking. However, support from significant others facilitated help-seeking (Wong et al., 2020). When investigating first-person accounts of FEP, one systematic review recommended planning and delivering mental health care by centering the service-user's needs (Griffiths et al., 2018); the reason being that many of our theoretical understandings of distress specific to psychotic experiences have typically paid more attention to service outcomes than service-user needs. The study went on to argue that this could have implications on what is prioritized in research, intervention, and care. With that in mind, these studies recommended more research focus on the facilitators and barriers to help-seeking for FEP.

There has been a growing body of qualitative studies on the lived experiences of FEP and their pathways to care, particularly meta-ethnographic studies on family and carer perspectives (Melton et al., 2020; Noirel et al., 2020; Wong et al., 2020; Cairns et al., 2014), as well as meta-analyses on pathways to service care for FEP. However, there has not been a meta-ethnography to date on the facilitators and barriers of help-seeking from the perspectives of people with personal accounts of FEP.

1.2. Aims for this meta-ethnography

This meta-ethnography aimed to answer the following questions:

1. What are the facilitators to help-seeking for FEP, from the perspectives of people with personal accounts of FEP?
2. What are the barriers to help-seeking for FEP, from the perspectives of people with personal accounts of FEP?

2. Methodology

2.1. Epistemological Position

The author of this meta-ethnography adopts a critical realist stance, which combines both a realist ontology and relativist epistemology (Bhaskar, 2013; Pilgrim, 2019). This stance acknowledges that not everyone who has FEP experiences find them distressing, concerning, or want to seek help for it (Cooke, 2020). Further, a critical realist position takes the stance that these statements contain important information about a phenomenon that does exist but is through a particular viewpoint and a socially-constructed world. Therefore, many of these statements by participants reflect their perceptions, rather than objective facts.

2.2. Systematic literature search

2.2.1. Search strategy

Search strategies in qualitative research can be used to increase search optimization when identifying relevant articles for a specific research question (Shaw et al., 2004). However, there is little guidance from empirical studies on the most effective strategy to use for qualitative research (Pearon et al., 2011). Therefore for this meta-ethnography, systematic reviews and empirical studies on retrieval methods were used to help guide and produce a transparent process for conducting effective search strategies (Booth, 2016; Pearson et al., 2011; Shaw et al., 2004).

The first method of the search strategy was the development of free-text terms and thesaurus terms to increase the search's sensitivity, relevance, and comprehensiveness. Broad-based terms were also included in the beginning of the search strategy (e.g. using terms such as "qualitative OR interview"). These terms (Table 1) were used as a search filter in eight electronic databases between September and October 2020: SCOPUS, ProQuest, OVID (Medline &

PsychInfo), PubMed, EBSCO (AMED & CINAHL), and Web of Science. MEDLINE and Web of Science were used as they were a recommended “optimal database combination” (Bramer et al., 2017). SCOPUS, ProQuest, PsychInfo, PubMed, and EBSCO were used as they contained large volumes of data from a diverse range of journals.

Table 1.

Search terms

Key words	Search terms derived from key words
Psychosis	First episode psychosis OR FEP OR duration of untreated psychosis OR DUP AND psychotic* OR voice hear* OR hearing voice*
Service-users	First person* OR first hand account* OR patient* OR lived experience* OR consumer* OR client* OR account*
Qualitative	Qualitative OR interview* OR experience* OR perspective* OR encounter*
Help-seeking	Disclosure* OR facilitator* AND help*
Barriers	Delay* OR DUP AND barrier* OR obstacle*

Reference checking was also used, which is a search strategy recommended for topics that uses varying terminology (Booth, 2016). The results were screened against an inclusion and exclusion criteria (Table 2).

Table 2.

Inclusion and Exclusion criteria

Inclusion	Exclusion	Rationale
English	Any other language (including translated articles)	The synthesis is completed in English and using other languages may lose the meanings inherent within the original language.
Adult population	Child Older Adults	Because the average age of onset for First Episode Psychosis (FEP) commonly occurs between the ages of 15 to 30 (Jones, 2013), studies were included if they used an age range lower than 18 as long as the study's population interest was not exclusively young people.
Qualitative studies	Quantitative, literature reviews, protocols, and descriptive-only qualitative analysis (e.g. word-frequency content analysis), "grey literature" (e.g. policy documents)	Studies had to have a qualitative exploratory investigation on personal accounts of FEP and help-seeking. Mixed-methods were considered if they had the relevant research aims and a qualitative interpretive-data analysis (e.g. thematic analysis) were used.

First-person accounts of FEP	Carers-only Family-only Healthcare professionals-only	If studies had carer and supportive network accounts, but also first-person accounts they were also included so long as perspectives could be distinguished between participants.
Participants who received a diagnosis of a Psychotic disorder	At-risk psychosis	The criteria and presentation for at-risk psychosis and psychosis, such as schizophrenia, are different (Addington et al., 2020).
Studies with research question (s) aimed at FEP and help-seeking	Studies that did not have at least 1 aim qualitatively exploring FEP and help-seeking	
Published articles	Postgraduate papers Unpublished studies	Postgraduate and unpublished studies were considered initially, however the search yielded enough relevant

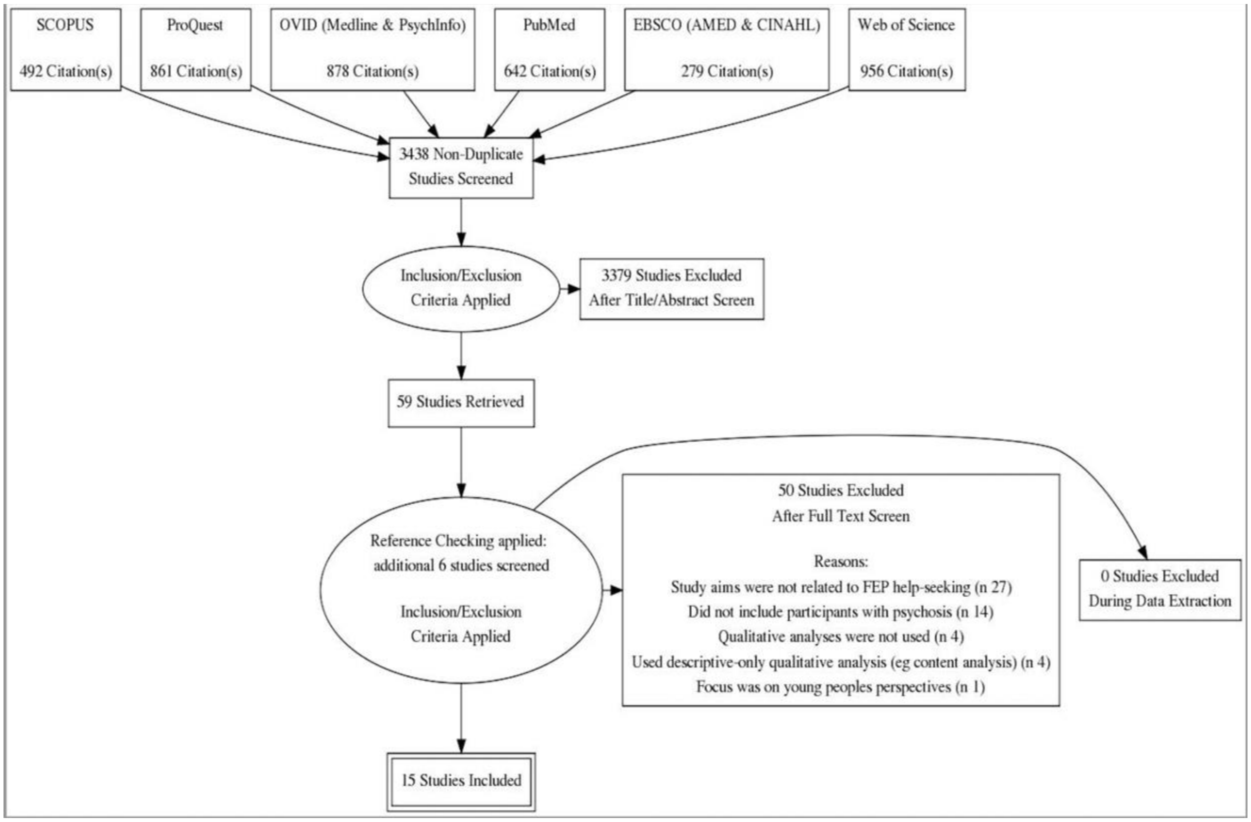
	published articles that explored the area of interest, making it possible to conduct a comprehensive review

2.2.2. Systematic Screening Process

The Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) model (Moher et al., 2009) was used to help illustrate each stage of the systematic selection process (Liberat et al., 2009) and how the inclusion and exclusion criteria were applied (Figure 1).

Figure 1.

PRISMA Flowchart illustrating the systematic screening process



A total of 4108 potentially relevant studies were identified using the search terms as filters in the electronic databases. After removing duplicates, titles and abstracts of the remaining 3438 studies were screened for inclusion or exclusion, which was based on the relevant population interest listed, study language, publication status, research aims, and other potentially relevant data listed in the abstract and title. Studies without abstracts, had missing descriptions of study aims and methods, or were not suitable based on the research aim were excluded, resulting in 3379 studies being excluded. A total of 59 potentially relevant studies were subject to full-text screening against the inclusion and exclusion criteria. Concurrently, reference checking was applied at this stage, yielding an additional 6 studies, totaling 65 full-text studies. 50 studies were then excluded after screening because the study aims were either not related to FEP help-seeking (n=27), did not include participants with psychosis (n=14), did not use qualitative analyses (n=4), only used descriptive qualitative analysis was (n=4), or the research aim was on young people (n=1). This resulted in a total of 15 studies remaining, which were subjected to data extraction and quality appraisal.

2.3. Data Extraction

2.3.1. S*tudy Characteristics*

Table 3.

A portion of the study characteristics (see Appendix A for the full table)

Author and year	**Country**	**Epistemological Position**	**Sample Size**	**Method & Analytic Tool**
Spikol & Murphy (2019)	Northern Ireland	Not stated	n=139	Qualitative:

				Interpretive Phenomenological Analysis (IPA)
Singh et al., (2013)	UK	Not stated	n= 25 (qualitative participant sample)	Mixed methods: Braun and Clarke’s (2006) Thematic Analysis
Jansen et al., (2015	Denmark	Social constructivism	n= 10	Qualitative: Braun and Clarke’s (2006) Thematic Analysis
Bay et al., (2016)	Norway	Not stated	n= 8	Qualitative: Systematic Meaning Condensation Procedure

Ferrari et al, (2018)	Canada	Not stated	n= 25	Qualitative: Braun and Clarke’s (2006) Thematic Analysis
Hardy et al., (2020)	USA	Not stated	n= 193	Qualitative: Braun and Clarke’s (2006) Thematic Analysis
Tanskanen et al., (2011)	UK	Not stated	n= 30	Qualitative: Braun and Clarke’s (2006) Thematic Analysis
Jansen et al., (2014)	Denmark	Not stated	n= 11	Qualitative: Braun and Clarke’s (2006) Thematic Analysis

Kamens et al., (2018)	USA	Not stated	n= 10	Mixed methods: Qualitative analysis utilized a modified version of Giorgi (2009) and Wertz's (2015) systematic phenomenological procedures
Cabassa et al., (2018)	USA	Not stated	n= 30	Qualitative: Grounded Theory Case Study methodology
Nordgaard et al., (2020)	Denmark	Not stated	n= 9	Qualitative: Braun and Clarke's (2006) Thematic Analysis
Macnaughton et al., (2015)	Canada	Constructivist	n= 12	Qualitative: Grounded Theory

				Narrative analysis
Bogen-Johnston et al., (2019)	UK	Not stated	n= 20	Qualitative: Braun and Clarke's (2006) Thematic Analysis
Melton et al., (2020)	USA	Social constructivist	n= 15	Qualitative: Grounded Theory
Judge et al., (2008)	USA	Not stated	n= 15	Qualitative: Grounded Theory Content Analysis

All 15 studies were conducted in the West (Table three): five in the United States (US) (Cabassa et al., 2018; Hardy et al., 2020; Judge et al., 2008; Kamens et al., 2018; Melton et al., 2020) three in the United Kingdom (UK) (Bogen-Johnston, 2019; Singh et al., 2013; Tanskanen et al., 2011), three in Denmark (Jansen et al., 2014; Jansen et al., 2015; Nordgaard et al., 2020), two in Canada (Ferrari et al., 2018; Macnaughton et al., 2015), one in Norway (Bay et al., 2016), and one in Northern Ireland (Spikol & Murphy, 2019). Most studies did not state an epistemological position; two studies claimed a social constructivist (Jansen et al., 2018; Melton et al., 2020) position and one a constructivist (Macnaughton et al., 2015) position. Every study included was qualitative-only except for two mixed-method studies (Kamens et al., 2018; Singh et al., 2013). 10 studies included only first-person accounts of FEP and the remaining used both first-person FEP accounts and caregivers (Cabassa et al., 2018; Hardy et al., 2020; Melton et al., 2020; Singh et al., 2013; Tanskanen et al., 2011). Sample sizes varied, with the largest study including 193 participants (Hardy et al., 2020), and the smallest 8 (Bay et al., 2016).

An interpretive qualitative analysis was used for each study; Braun and Clarke's (2006) Thematic Analysis was used most (Bogen-Johnston et al., 2019; Ferrari et al., 2018; Hardy et al., 2020; Jansen et al., 2014; Jansen et al., 2015; Nordgaard et al., 2020; Singh et al., 2013; Tanskanen et al., 2011), followed by Grounded Theory for one study (Melton et al., 2020) and three studies combining grounded theory with case study methodology (Cabassa et al., 2018), content analysis (Judge et al., 2008), or narrative analysis (Kamens et al., 2018). Two studies used phenomenological analysis; one used Interpretive Phenomenological Analysis (IPA) (Spikol & Murphy, 2009) and the other Wertz's (2019) systematic phenomenological procedures (Kamens et al., 2018). Finally, one study used a systematic meaning condensation procedure for their analysis (Bay et al., 2016).

2.3.2. Participant Characteristics

Table 4.

A portion of the participant characteristics (See Appendix B for full table)

Author and year	**Participants age**	**Gender**	**Ethnicity**
Spikol & Murphy (2019)	18 – 29	Not listed	Not listed
Singh et al., (2013)	Not listed (only demographic data	Not listed (only demographic data	5 black service-users 5 black carers

	listed for quantitative analyses)	listed for quantitative analyses)	5 Asian service-users 4 Asian carers 4 white service-users 4 white carers
Jansen et al., (2015	18-27, median age= 21	5 males 5 females	Ethnic Danish
Bay et al., (2016)	17-44	4 males 4 females	Not listed
Ferrari et al, (2018)	Mean age= 26 years old	13 males 12 females	3 male Africans 3 male Caribbean 7 male Europeans 2 female Africans 1 female Caribbean 9 female Europeans
Hardy et al., (2020)	Not listed	Not listed	Not listed
Tanskanen et al., (2011)	Mean age= 23.5	15 males 6 females	3 White-British 4 White “other” 3 Black Africans

			5 Black Caribbean 4 Asian Bangladeshi 2 Mixed Race
Jansen et al., (2014)	15-24, median age= 20	6 males 5 females	Ethnic Danish
Kamens et al., (2018)	Mean age= 22.5	6 males 4 females	2 African American 3 Mixed-Race 4 White 1 not listed
Cabassa et al., (2018)	Mean age= 23.7	11 males 9 females	11 Hispanic 5 African American 10 non-Hispanic White 2 Asian
Nordgaard et al., (2020)	Mean age = 27.3	4 males 5 females	Not listed
Macnaughton et al., (2015)	20-32, median age= 26	6 males 6 females	4 Anglo-Europeans 4 East Asian

			3 non-Anglophone European 1 South Asian
Bogen-Johnston et al., (2019)	Mean age= 25	12 males 8 females	Not listed
Melton et al., (2020)	Mean age= 24	Not listed	Not listed
Judge et al., (2008)	Mean age= 24.4	8 males 7 females	12 Caucasian 2 African American 1 Asian

In total, 552 participants were included for review. It was not possible to summarize mean ages across all studies; 5 studies used median age intervals (Bay et al., 2016; Jansen et al., 2015; Jansen et al., 2014; Macnaughton et al., 2015; Spikol & Murphy, 2019), one study did not list age ranges (Hardy et al., 2020), and one study only listed age ranges and other demographic information (e.g. gender) for its quantitative sample, but not its qualitative (Singh et al., 2013). Eight out of 15 studies reported its mean ages (Bogen-Johnston et al., 2019; Cabassa et al., 2018; Kamens et al., 2018; Ferrari et al., 2018; Judge et al., 2008; Melton et al., 2020; Nordgaard et al., 2020; Tanskanen et al., 2011), yielding a total mean age of 24.55 (SD= 1.52).

Equally, it was not possible to summarize genders across all 15 studies, as four studies did not report the genders of participants (Hardy et al., 2020; Melton et al., 2020; Singh et al., 2013; Spikol & Murphy, 2019). The remaining 11 yielded a total of 90 males and 71 females. It was also not possible to summarize ethnicities across studies; most had different definitions, reporting, and categories for ethnic compositions depending on the country the study was conducted in. For example, some North American studies reported ethnicities as "Asian" (Judge et al., 2008), while UK studies distinguished "Asian Bangladeshi" participants from "East Asian" (Tanskanen et al., 2011).

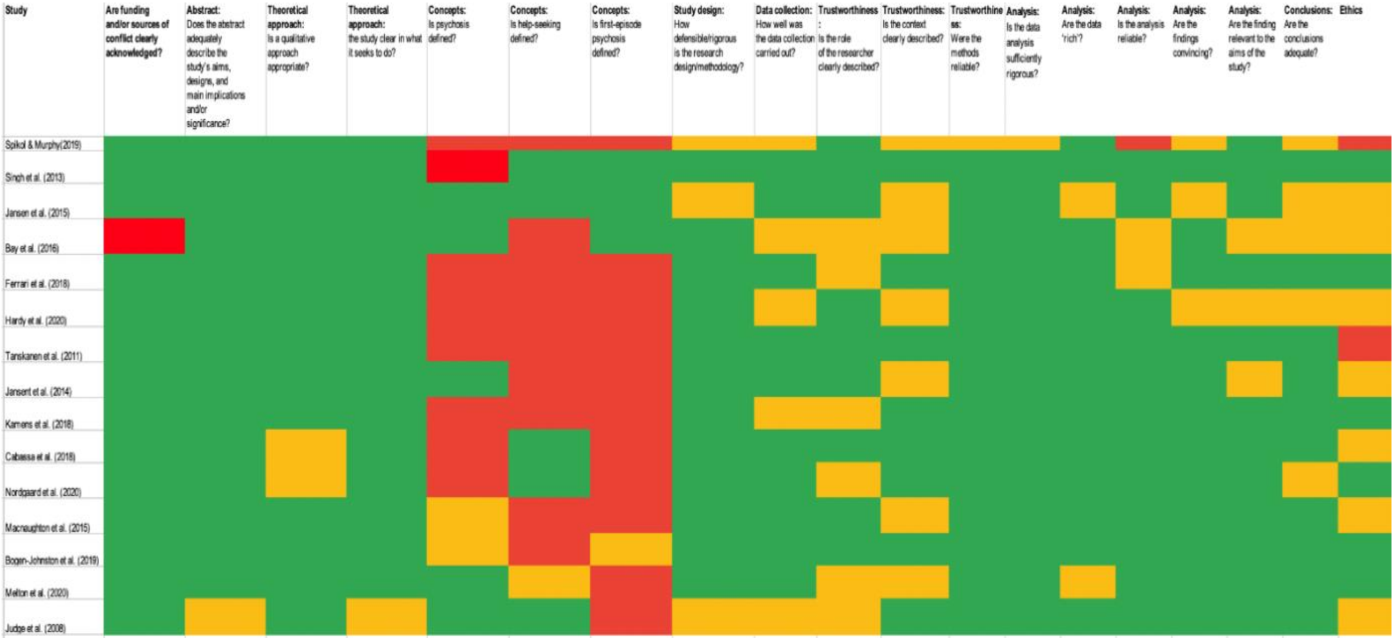
2.3.3. Quality Appraisal

Appraising qualitative studies promotes an opportunity to critically review methodological rigor and credibility of conclusions (Majid & Vanstone, 2018), which is becoming a common process to undergo when conducting meta-ethnographies (Munthe-Kaas et al., 2019; Thorne, 2016). For this meta-ethnography, the author created a 19-item checklist (Appendix C), combining two qualitative standards checklists (American Psychological Association, 2018; NICE, 2012). Three additional items were included, which were related to assessing a study's conceptual clarity (namely, psychosis, FEP, and help-seeking); this was done with the help of the author's research supervisor and a meta-ethnography support group she was participating in (Toye et al., 2013). Third, the author met with her research supervisor and support group for reflexive dialogue in order to have more than one appraiser review the quality of the studies, as well as have a more holistic approach throughout the appraisal process.

All papers were measured against the checklist and two grid tables were created: the first table was to track descriptive data on how, when, and where parts of the criterion where met or not (see Appendix D); the second table was a color-coded visual illustration of the criteria where the color "green" was used to mark if the criterion was met, "yellow" if the criterion was partially met or unclear, and "red" if the criterion was not met (Figure 2). To determine if a study met or partially met quality standards it had to have demonstrated a clear theoretical rationale and study design, a consideration of the roles of the researchers in relation to the methodology and analysis, and a reliable and clear analysis that helped justify the conclusions in relation to their research aim (s). All 15 studies met or partially met most of the criteria listed; strengths noted across studies included the reporting of a theoretical approach, providing justifications for a qualitative approach to be used, and demonstrating reliability and rigor. The quality varied across studies in regard to how data collection and analyses was described, including researcher roles, ethical approval, and conclusions. Most studies did not meet the criteria in reporting how psychosis concepts were defined or considered.

Figure 2.

Quality Appraisal of studies: color-coded.



Study	**Are funding and/or sources of conflict clearly acknowledged?**	**Abstract:** Does the abstract adequately describe the study's aims, designs, and main implications and/or significance?	**Theoretical approach:** Is a qualitative approach appropriate?	**Theoretical approach:** the study clear in what it seeks to do?	**Concepts:** Is psychosis defined?	**Concepts:** Is help-seeking defined?	**Concepts:** Is first-episode psychosis defined?	**Study design:** How defensible/rigorous is the research design/methodology?	**Data collection:** How well was the data collection carried out?	**Trustworthiness :** Is the role of the researcher clearly described?	**Trustworthiness:** Is the context clearly described?	**Trustworthiness:** Were the methods reliable?	**Analysis:** Is the data analysis sufficiently rigorous?	**Analysis:** Are the data 'rich'?	**Analysis:** Is the analysis reliable?	**Analysis:** Are the findings convincing?	**Analysis:** Are the finding relevant to the aims of the study?	**Conclusions:** Are the conclusions adequate?	**Ethics**
Spikol & Murphy(2019)	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟨	🟨	🟩	🟨	🟨	🟨	🟩	🟥	🟨	🟩	🟨	🟥
Singh et al. (2013)	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Jansen et al. (2015)	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟨	🟩	🟩	🟨	🟩	🟨	🟩	🟨	🟨
Bay et al. (2016)	🟥	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟨	🟨	🟨	🟩	🟩	🟩	🟨	🟩	🟨	🟨	🟨
Ferrari et al. (2018)	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟩	🟩	🟨	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩	🟩
Hardy et al. (2020)	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟩	🟨	🟩	🟨	🟩	🟩	🟩	🟩	🟨	🟨	🟨	🟨
Tanskanen et al. (2011)	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟥
Jansent et al. (2014)	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟩	🟩	🟩	🟨	🟩	🟩	🟩	🟩	🟩	🟨	🟩	🟨
Kamens et al. (2018)	🟩	🟩	🟩	🟩	🟥	🟥	🟥	🟩	🟨	🟨	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Cabassa et al. (2018)	🟩	🟩	🟨	🟩	🟥	🟩	🟥	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨
Nordgaard et al. (2020)	🟩	🟩	🟨	🟩	🟥	🟩	🟥	🟩	🟩	🟨	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟩
Macnaughton et al. (2015)	🟩	🟩	🟩	🟩	🟨	🟥	🟥	🟩	🟩	🟩	🟨	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨
Bogen-Johnston et al. (2019)	🟩	🟩	🟩	🟩	🟨	🟥	🟨	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Melton et al. (2020)	🟩	🟩	🟩	🟩	🟩	🟨	🟥	🟩	🟩	🟨	🟨	🟩	🟩	🟨	🟩	🟩	🟩	🟩	🟩
Judge et al. (2008)	🟩	🟨	🟩	🟨	🟩	🟩	🟥	🟨	🟨	🟨	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨

2.3.4. Theme extraction

This meta-ethnography followed Noblit and Hare's (1988) guidance on conducting meta-ethnographies, which consisted of steps to follow or "phases" (Table 5). Phases "Getting started" and "deciding what is relevant" was completed during the formation of the research question and the systematic search and review.

Table 5.

Noblit and Hare's (1988) phases for completing a meta-ethnography.

Meta-ethnography Phases (Noblit & Hare, 1988)	**Steps taken in this meta-ethnography during each phase**
Getting started	Reading literature and studies to form a qualitative interest and research question
Deciding what is relevant	Systematic searches and reviews
Reading the studies	Full-text screenings, data extractions, quality appraisals, theme extractions
Determining how the studies are related	Repeated reading of studies included for review to determine relationships that will be later synthesized

	Making a list of key metaphors, ideas, phrases, concepts, and juxtapositions used in each study
Translating the studies into one another	Comparing studies to the other and how they interact, including their metaphors, ideas, concepts
Synthesizing translations	Comparing studies to the other and how they interact, including their metaphors, ideas, concepts[1]
	Analyzing competing interpretations and translating them into one another
Expressing the synthesis	Writing down the themes

Phases “reading the studies” and “determining how the studies are related” were followed next. This consisted of first extracting themes and subthemes of each study onto an extraction grid via Microsoft Excel (Figure 3).

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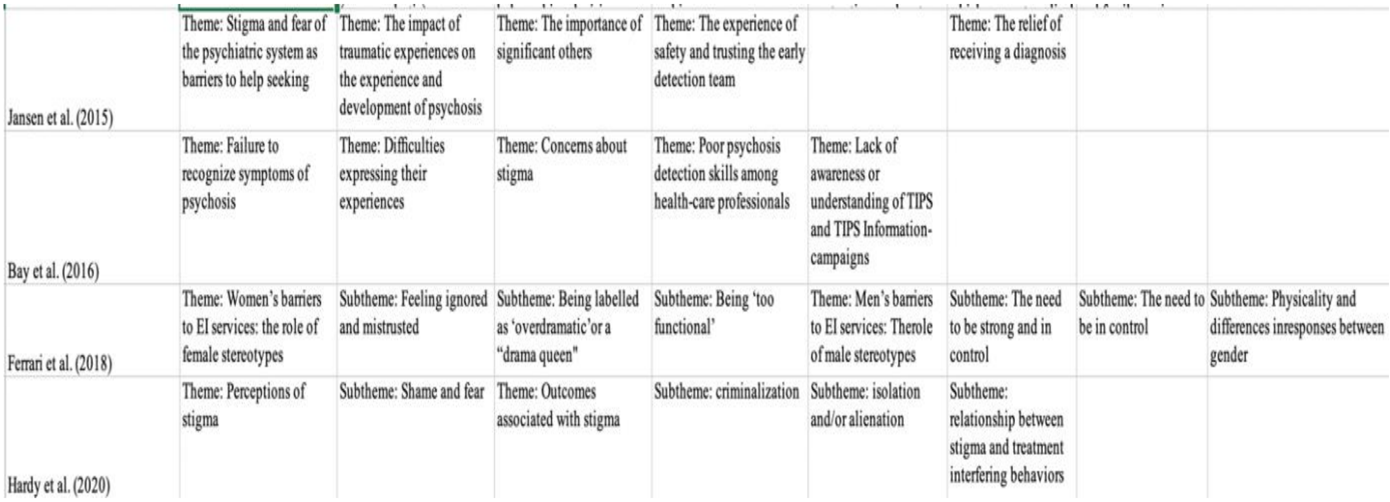
[1] The “Synthesizing translations” phase was described in Noblit & Hare (1988) as containing the same steps as the phase “Translating the studies into one another”, hence the step being repeated.

Figure 3.

Portion of data extraction: Themes (See Appendix D for the completed data extraction).



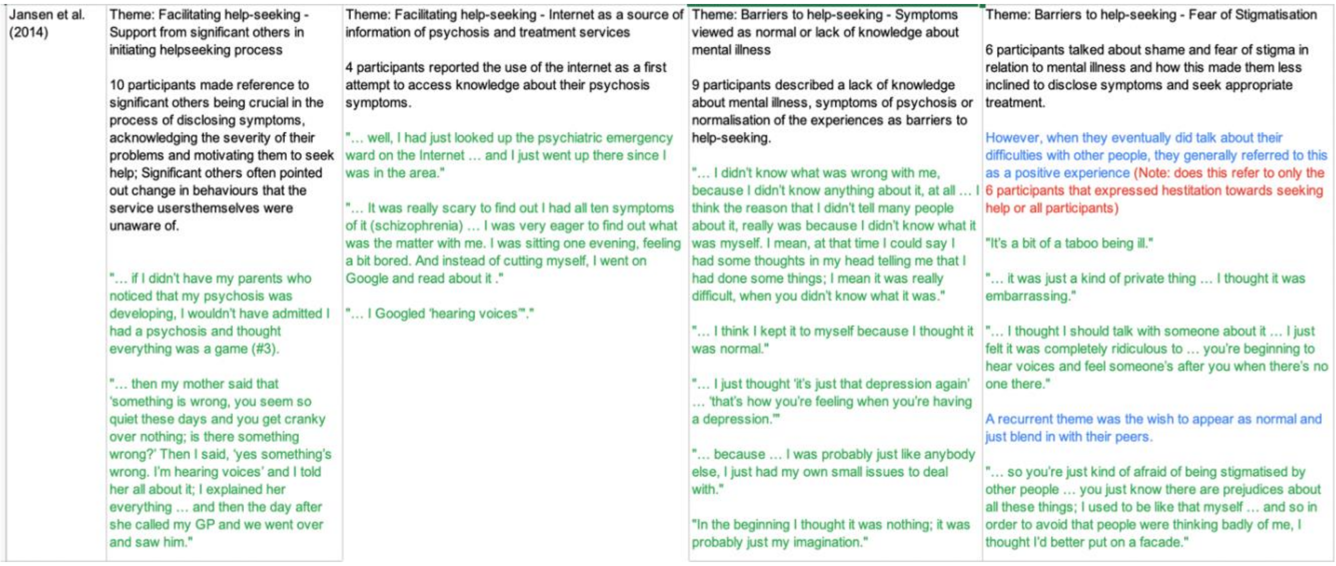
Jansen et al. (2015)	Theme: Stigma and fear of the psychiatric system as barriers to help seeking	Theme: The impact of traumatic experiences on the experience and development of psychosis	Theme: The importance of significant others	Theme: The experience of safety and trusting the early detection team		Theme: The relief of receiving a diagnosis		
Bay et al. (2016)	Theme: Failure to recognize symptoms of psychosis	Theme: Difficulties expressing their experiences	Theme: Concerns about stigma	Theme: Poor psychosis detection skills among health-care professionals	Theme: Lack of awareness or understanding of TIPS and TIPS Information-campaigns			
Ferrari et al. (2018)	Theme: Women's barriers to EI services: the role of female stereotypes	Subtheme: Feeling ignored and mistrusted	Subtheme: Being labelled as 'overdramatic'or a "drama queen"	Subtheme: Being 'too functional'	Theme: Men's barriers to EI services: Therole of male stereotypes	Subtheme: The need to be strong and in control	Subtheme: The need to be in control	Subtheme: Physicality and differences inresponses between gender
Hardy et al. (2020)	Theme: Perceptions of stigma	Subtheme: Shame and fear	Theme: Outcomes associated with stigma	Subtheme: criminalization	Subtheme: isolation and/or alienation	Subtheme: relationship between stigma and treatment interfering behaviors		

Note. As listed from left to right: study titles, themes, and subthemes.

Next, studies were read and re-read, with comparative accounts noted, including the use of metaphors, ideas, concepts, phrases, and juxtapositions (Figure 4).

Figure 4.

A portion of the list of metaphors, ideas, concepts, phrases, and juxtapositions that were written down (See Appendix E for the completed list)



Jansen et al. (2014)	Theme: Facilitating help-seeking - Support from significant others in initiating helpseeking process 10 participants made reference to significant others being crucial in the process of disclosing symptoms, acknowledging the severity of their problems and motivating them to seek help; Significant others often pointed out change in behaviours that the service usersthemselves were unaware of. "… if I didn't have my parents who noticed that my psychosis was developing, I wouldn't have admitted I had a psychosis and thought everything was a game (#3). "… then my mother said that 'something is wrong, you seem so quiet these days and you get cranky over nothing; is there something wrong?' Then I said, 'yes something's wrong. I'm hearing voices' and I told her all about it; I explained her everything … and then the day after she called my GP and we went over and saw him."	Theme: Facilitating help-seeking - Internet as a source of information of psychosis and treatment services 4 participants reported the use of the internet as a first attempt to access knowledge about their psychosis symptoms. "… well, I had just looked up the psychiatric emergency ward on the Internet … and I just went up there since I was in the area." "… It was really scary to find out I had all ten symptoms of it (schizophrenia) … I was very eager to find out what was the matter with me. I was sitting one evening, feeling a bit bored. And instead of cutting myself, I went on Google and read about it ." "… I Googled 'hearing voices'"."	Theme: Barriers to help-seeking - Symptoms viewed as normal or lack of knowledge about mental illness 9 participants described a lack of knowledge about mental illness, symptoms of psychosis or normalisation of the experiences as barriers to help-seeking. "… I didn't know what was wrong with me, because I didn't know anything about it, at all … I think the reason that I didn't tell many people about it, really was because I didn't know what it was myself. I mean, at that time I could say I had some thoughts in my head telling me that I had done some things; I mean it was really difficult, when you didn't know what it was." "… I think I kept it to myself because I thought it was normal." "… I just thought 'it's just that depression again' … 'that's how you're feeling when you're having a depression.'" "… because … I was probably just like anybody else, I just had my own small issues to deal with." "In the beginning I thought it was nothing; it was probably just my imagination."	Theme: Barriers to help-seeking - Fear of Stigmatisation 6 participants talked about shame and fear of stigma in relation to mental illness and how this made them less inclined to disclose symptoms and seek appropriate treatment. However, when they eventually did talk about their difficulties with other people, they generally referred to this as a positive experience (Note: does this refer to only the 6 participants that expressed hestitation towards seeking help or all participants) "It's a bit of a taboo being ill." "… it was just a kind of private thing … I thought it was embarrassing." "… I thought I should talk with someone about it … I just felt it was completely ridiculous to … you're beginning to hear voices and feel someone's after you when there's no one there." A recurrent theme was the wish to appear as normal and just blend in with their peers. "… so you're just kind of afraid of being stigmatised by other people … you just know there are prejudices about all these things; I used to be like that myself … and so in order to avoid that people were thinking badly of me, I thought I'd better put on a facade."

Note. Red font indicates comments/reflections from the author of this meta-ethnography, green font indicates participant quotes, and blue font indicates comments/reflections from the authors.

2.4. Data analysis and synthesis

To complete phases “translating the studies into one another” and “synthesizing translations”, Noblit and Hare (1988) suggest “key judgments calls” (p.37) when considering if studies are comparable (reciprocal), in opposition (refutational), or taken together to form a “line of argument” (p.38-40). Steps in determining this, however, are not provided and left open to interpretation in how they should be operationalized (Campbell et al., 2011). Therefore, two levels of synthesis (France et al., 2019) were used during these phases.

2.4.1. Level-one synthesis

Level-one synthesis involved a re-reading of accounts with extensive attention, as well as a systematic comparison and identification of concepts, metaphors and themes in relation to the other (France et al., 2019). First, similar themes were grouped into categories of shared meaning (Appendix F), such as participants expressing concerns of people’s perceptions in one study and discussing stigma in another; this was considered “reciprocal translation.” Second, to balance homogeneity and heterogeneity in the studies, any refutational data, such as how participants experienced services, were considered in how they can be translated and synthesized in a manner that demonstrated coherence. This led to discussions with the author’s research supervisor and support group; it was found that some ideas, whilst seeming refutational, could be contextualized within the findings. The first level of synthesis resulted in several translations that were merged and retranslated into single translations. Ideas that were neither completely reciprocal nor refutational required a second level of synthesis.

2.4.2. Level-two synthesis

Level-two synthesis involved a process of using the findings of individual studies to identify overarching concepts and possibly develop new interpretations. This level included elements of a line-of-argument synthesis, in which a new theory is developed to explain a phenomenon (France et al., 2019; Noblit & Hare, 1988). Level-two also included several critical discussions between the author and her research supervisor to ensure reliability and representativeness of findings. First, ideas, concepts, themes, and metaphors that could be neither translated as reciprocal nor refutational were read and re-read to determine interactions and relationships between them. Second, interactive and emerging concepts were translated and contextualized, yielding new interpretations across accounts (Appendix G), but it was not enough to solidify a new theory. Instead, ideas and concepts were developed, translated, and demonstrated a more narrative process of FEP and help-seeking (Table 6). Following level-two synthesis, the meta-ethnography moved to the phase "expressing the synthesis", consisting of five themes and six sub-themes.

Table 6.

Meta-ethnography themes: The facilitators and barriers to help-seeking for people with FEP.

Themes	**Sub-themes**
3.1 Initial certainty in interpreting experiences	3.11 Contextualizing experiences 3.12 Normalizing experiences
3.2 Growing uncertainty leading to different explanations	3.2.1 Growing uncertainty 3.22 Developing alternative frameworks of understanding

3.3 The role of significant others in help-seeking	3.3.1 Family involvement
	3.3.2 Concerns about other people’s perceptions
3.4 The role of services in help-seeking (or not)	
3.5 The tipping point	

3. Findings

3.1. Theme 1: Initial certainty in interpreting experiences

Across all studies, most participants described that at the emergence of psychotic-like experiences, they initially contextualized or normalized subtle changes happening to their thoughts, emotions, and/or behaviors, including gradual changes in concentration (Bay et al., 2016, p. 73) and "not feeling like oneself" (Cabassa et al., 2018, p. 4). They seemed to first interpret these experiences as a consequence to a related psychosocial event or a transitory phase, thereby not perceiving any form of help-seeking as necessary. Some authors speculated this was an attempt to grant a feeling of certainty over what was happening, regain control, and set an expectation that these experiences will not "become that big" (Cabassa et al., 2018, p.4.).

The crux of help-seeking at this stage appears to be based on having prior knowledge of FEP or mental health-related issues. Across the studies, there was a small subset of participants that recognized the significance of some of the changes in experiences. Rather than normalizing or contextualizing, they either knew something "wasn't right" (Spikol & Murphy, 2019, p.16) and sought general help-seeking, contacted a mental health service after using the internet for information about their experiences (Jansen et al., 2015, p.88), or disclosed to a significant other when their experiences involved hallucinations (Melton et al., 2020, p.1125).

3.1.1. Subtheme: Contextualizing Experiences

When contextualizing the initial phenomenological changes of psychosis (or what authors referred to as the "prodromal phase"), it was common to attribute changes to stress (Ferrari et al., 2018, p.357; Judge et al., 2008, p.97; Nordgaard et al., 2020, p.6; Singh et al., 2013, p.36) sleep deprivation (Spikol & Murphy, 2019, p.10; Tanskanen et al., 2011, p.4) and substance misuse (Cabassa et al., 2018, p.4; Ferrari et al., 2018, p.357; Melton et al., 2020, p.1125; Spikol &

Murphy, 2019, p.24; Tanskanen et al., 2011, p.4). Further, some participants' friends and family contextualized and attributed these experiences to "teenage issues" (Bay et al., 2016, p.73; Cabassa et al., 2018, p.4; Melton et al., 2020, p.1125; Tanskenen et al., 2011, p.4). When a mental health problem was suspected, depression was most the most common explanation (Bay et al., 2016, p.73; Ferrari et al., 2018, p.357; Jansen et al., 2015, p.89; Macnaughton et al., 2015, p.295; Tanskanen et al., 2011, p.4). In other words, changes occurring were not initially seen as atypical or unusual in the early stages, but instead was due to an event, stressor, or developmental process.

3.1.2. Subtheme: Normalizing Experiences

When changes were seen as unusual or if a participant felt they were being "split off from reality," (Macnaughton et al., 2015, p.295), most reported that they did not seek help at this stage because they believed it to be a passing, transitory phase, thereby normalizing the experiences. It appears that part of the process of normalizing included assimilating these atypical aspects to themselves as something either "perfectly normal" (Tanskanen et al., 2011, p. 3), that it was "just the way [they] were" (Judge et al., 2008, p.97), or that it was a passing phase (Bay et al., 2016, p.73; Jansen et al., 2015, p.4; Macnaughton et al., 2015, p.295). One participant in particular characterized normalization as such:

> *"The doctors asked [about voices], but I related it to my actual self. It was that close" (Judge et al., 2008, p.97)*

3.2. Theme 2: Growing uncertainty leading to different explanations

As FEP experiences intensified, two things appeared to occur: one, participants developed a "cloud of uncertainty" (Cabassa et al., 2018. P.5) and doubted their initial interpretation of their experiences, and two, participants generated "explanatory models" (Judge et al., 2008, p.97) to accommodate contradictory, confusing, and uncertain ideas and beliefs.

3.2.1. Subtheme: Growing uncertainty

Growing feelings of uncertainty was reported across studies. It is unclear why, as participants themselves had a difficult time articulating it:

> *"I wasn't feeling [like] myself, and things were strange... and it was hard to put into words because it was so complicated" (Judge et al., 2008, p.98)*

Some participants pointed to examples of where the shift in certainty might have occurred, such as noticing contradictions between their initial attributions and "extensive reality-testing behaviors with the respondent [being] unable to fully trust their senses" (Spikol & Murphy, 2019, p.13). Other participants, as well as the researchers who authored the studies, suggested that while they initially understood these experiences as circumstantial and related to recent events, it became increasingly difficult to continue to contextualizing or normalizing these experiences (Cabassa et al., 2018, p.5; Judge et al., 2008. P.98; Singh et al., 2013, p.39; Tanskanen et al., 2011, p.5). For example, one participant commented:

> *"Is it the world that is sick or is it me? Because I seem to have such a high level of functioning and ... how to put it... When is it normal to just have a bad day, and when is it something mental?" (Nordgaard et al., 2020, p.8)*

The apparent difficulty in describing the uncertainty both presently and retrospectively suggests it may have impacted help-seeking at this stage, in particular with participants reported using self-reliance to cope rather than seek support (Bay et al., 2016, p.73; Cabassa et al., 2018, p.4).

3.2.2. Subtheme: Developing alternative frameworks of understanding

Despite the feelings of uncertainty, most still had a "need to figure out what's going on" (Judge et al., 2008, p.98), with participants relying on a variety of frameworks to help make sense of these changes. Although explanatory models may have been generated to help them better understand, it seems it also contributed to a delay in help seeking as it reportedly affected their ability to notice if their experiences were beginning to or had become a problem (Bogen-Johnston et al., 2019, p.1310).

Most frameworks used appeared to be those that already fit with the participant's cultural, religious, and historical factors (Singh et al., 2013, p.40), with the most common being victim/persecuted and religious/cultural. Being persecuted or the victim of authority figures, the government, parents, and friends was seen across the studies:

> *"I eventually, to make sense of my paranoid delusions, came up with a rationale that my head (mind) was the centre of a[n] on-line reality*

> *show that preyed on my deep sense of intuitiveness" (Macnaughton et al., 2015, p.295)*

For some, this led to help-seeking; the belief that they were being targeted led to contacting emergency services, which sometimes led to healthcare services (Nordgaard et al., 2020, p.9; Spikol & Murphy, 2019, p.15). One participant in particular sought help based on this framework:

> *"For Patient 2, who was convinced that she was being kept under surveillance but did not know by whom or for what exact purpose, it was not clear where to seek help. Thus, she asked her neighbours, colleagues, and even an accountant for help before finally calling her general practitioner, who suggested her to go the psychiatric emergency room" (Nordgaard et al., 2020, p8)*

Religious and spiritual frameworks were also common, particularly among ethnic minorities, and were characterized by authors as being a barrier to help-seeking, with some participants reporting to have believed that these intensifying experiences were due to "demons...lifestyle...Harry Potter" (Judge et al., 2008, p.97), which required a change in their own lifestyle than seeking help. Some participants also reported to have kept holy water at their bedside (Spikol & Murphy, 2019, p.16) or protection amulets to guard them against evil spirits (Singh et al., 2013, p. 38). Moreover, some sought religious agencies as a form of help-seeking, which either facilitated or delayed help-seeking from mental health services, depending on the advice of their faith leaders (Singh et al., 2013, p.38; Spikol & Murphy, 2019, p.15; Tanskanen et al., 2011, p.4). For example, one carer recounted:

> *"Their [church] response was they were praying for him and encouraged him to come [to hospital]...I think really that was his saving grace, that gave him insight. Because when he got sectioned [compulsorily detained] after that he continued to go to the church and today he is a strong man of the Lord. So I really do believe that that has pulled him through" (Tanskanen et al., 2011, p.7)*

3.3. Theme 3: The role of significant others in help-seeking (or not)

There appears to be a relationship between frameworks used and the consequent progressive disturbance in the participants' behavior, communication, emotional expression, and physical presentation (Melton et al., 2020, p.1123; Spikol & Murphy, 2019, p.13), as it is usually at this point that familial/social networks begin noticing these changes and play a significant role on help-seeking (Kamens et al., 2018, p.312).

3.3.1. Subtheme: Family involvement

Helpful family involvement included acknowledging the severity of the problems, pointing out changes in behaviors (Jansen et al., 2014, p.87) and encouraging participants to seek help (Tansakenen et al., 2011, p.5). It also involved finding appropriate services and treatment (Hardy et al., 2020, p.275), "asking for good doctors" (Singh et al., 2013, p.37), as well as assisting in other areas, including "contacting schools, [and] accompanying [them] at meetings." (Jansen et al., 2015, p.87). If there was a history of mental health difficulties, it also aided the families' recognition of FEP (Bogen-Johnston et al., 2019, p.1312). Further, family members were usually recognized by participants as having a crucial role in “just [being] there” (Jansen et al., 2015, p.87), as participants disclosed their experiences to them. Where family involvement was not possible or preferred by the participant, a supportive network of friends was reported as important in facilitating help-seeking, with some participants describing a stepwise process of disclosing to friends, then family, and then seeking treatment (Jansen et al., 2014, p.4; Jansen et al., 2015, p.88; Nordgaard et al., 2020, p.8). One participant described the process as such:

> *“… because now I had explained the story to … yes, first to her in XXX and then to my best friend called XXX, and then to another in the same weekend that I explained my mother … so that’s how it started.” (Jansen et al., 2015, p.88)*

While another participant provided an example of how a conversation with a friend led to help-seeking from a healthcare professional:

> *“Then I asked my close friend how often he had such experiences – but he never did. That was unfortunate. Then I asked him about other experiences, but he also didn’t recognize those...Then I asked him if he thought I should see a doctor and he said that it was probably a good idea.” (Nordgaard et al., 2020, p.8)*

In contrast, less helpful family involvement involved an absence of support and active listening, as well as misattributions or dismissals after the psychosis had already increased in severity (Judge et al., 2008, p.97; Melton et al., 2020, p.1124; Nordgaard et al., 2020, p.9; Singh et al., 2013, p.39; Tansakanen et al., 2011, p.6) – all of which was linked to delayed help-seeking. For example, one participant recalled:

> *"Patient 7 told her mother that she was hearing people who were not present talking to her. Her mother responded to her by saying that it was probably just ghosts, and she did not return to the issue or take any kind of action in relation to this. The patient described that after this, she did not seek help for a long time" (Nordgaard et al., 2020)*

Some participants described feeling "ashamed…[their] parents believed it to be their fault" (Hardy et al., 2020, p.274). Further, when family members consulted wider familial/social networks they were "discouraged [to make] contact with mental health services" (Tanskenen et al., 2011, p.6). Gender stereotypes also appeared to play a role in family involvement: expectations of males being "strong and in control…[which would] stem from an obligation to families and extended families" (Ferrari et al., 2018, p.359) were linked to a delay in help-seeking, as their role within the family would take precedence over individual distress since help-seeking was not a "male sort of thing to do"(Bogen-Johnston et al., 2019, p.1313).

3.3.2. Subtheme: Concerns about people's perceptions

Concerns about people's perceptions appeared to delay help-seeking. Some participants described disguising symptoms due to social belongingness, "[wanting] to appear normal… (not like someone who is) weird and [hears] voices" (Jansen et al., 2015, p.90). Some also said they had concerns of exacerbating or "making worse" another family member's mental health-related difficulties and stress (Bogen-Johnston et al., 2019, p.1312; Jansen et al., 2014, p.4), as well as having a fear of being seen as "crazy or made fun of" (Hardy et al., 2020, p.275) by friends, family, or employers. Delays in help-seeking may also have been influenced by fears of potential consequences in using psychiatric services, with some participants describing a refusal of "medications to avoid being labeled as mentally ill" (Cabassa et al., 2018, p.5) and families not "[wanting] this [psychotic] incident to get in the way of future alliances from respectable families" (Singh et al., 2013, p.41). These concerns were not completely baseless, as some participants reported that some of their peers did indeed "[drop] having contact with" after they disclosed their FEP to them (Hardy et al., 2020, p.274).

3.4. Theme 4: The role of services in help-seeking (or not)

The perceived quality of mental health care was identified as important in shaping pathways to care, with the likelihood of help-seeking from services depending on past interactions with services (Cabassa et al, 2018, p.6) and cultural norms and expectations (Singh et al., 2013, p.41; Tanskenen et al., 2011, p.7). Relationships between services and service-user were particularly important in perceiving services as supportive and helpful, with one participant reporting:

> *"They were listening and came up with suggestions, because I'm having difficulties opening up, so they were fishing in the right way. They were calm and took all the time needed" (Jansen et al., 2014, p.4).*

Further, how services provided and described diagnoses appeared to be important in how participants perceived their care by services (Jansen et al., 2014, p.4; Macnaughton et al., 2015, p.295). Participants characterized low quality of care as receiving unclear information about treatment options and side effects (Cabassa et al., 2018, p.6), inappropriate referrals (Nordgaard et al., 2020, p.9), misdiagnoses (Bay et al., 2016, p.74), and insensitive and poor treatment from healthcare professionals (Tanskanen et al., 2011, p.7). These examples were linked to longer delays to help-seeking (Kamens et al., 2018, p.311), including police arrests (Ferrari et al., 2018, p.359; Singh et al., 2013, p.41), gender stereotypes (Ferrari et al., 2018, p.359), and medication refusal due to distrust of services by the individuals experiencing FEP and their significant others (Hardy et al., 2020, p.274; Tanskenen et al., 2011, p.7).

Negative pathways to care that led to delayed help-seeking also included “fragmented transitions” between family, community, and service involvement (Cabassa et al., 2018). There were several examples demonstrating this, such as being referred to services without being given an address or told where it was located (Nordgaard et al., 2020, p.9), school, occupational health, and religious/community settings noticing deterioration in participants but not referring them to a mental health service (Tanskanen et al., 2011), and not receiving clear courses of action for follow-up care (Cabassa et al., 2018, p.6).

There were ethnic differences found that were related to help-seeking. While all ethnicities struggled in accessing care, Black, Asian, and other ethnic minorities reporting feeling misapprehension towards healthcare providers and in police involvement, as well as concerns in the type of treatment they would receive based on their ethnicity (Singh et al., 2013, p.4; Tanskanen et al., 2011, p.5). On the other hand, White participants expressed concern in the quality of care they would receive, such as lack of available beds, rather than their ethnicity (Singh et al., 2013, p.41).

3.5. Theme 5: The tipping point

If participants were not able to successfully seek help either through significant others, services, or self-referrals, what appeared to occur was the culmination of a crisis or a "tipping point". As participants reached a "a point of desperation" (Bogen-Johnston et al., 2019, p.1311), help-seeking was seen as a final course of action.

Beyond experiencing significant distress, the "tipping point" appears to be characterized as exhausting all options from "jobs, friends….family doctor, psychotherapists, and naturopathy" (Macnaughton et al., 2015, p.295), fear of job loss or educational opportunities (Nordgaard et al., 2020, p.6), worsening social situations (Nordgaard et al., 2020, p. 6; Singh et al., 2013, p.40), homelessness (Bogen-Johnston et al., 2019, p.1311), and "[running out] of less threatening explanations for their predicament" (Macnaughton et al., 2015, p.295) that may have previously prevented them from seeking help. Participants' families noticing visible physical deterioration also appeared to lead to help-seeking, especially if they were becoming "extremely thin" (Melton et al., 2020, p.1125), were shaking (Nordgaard et al., 2020, p.8), or if they believed there was a physical health health emergency (e.g., heart attack) (Melton et al., 2020, p.1125; Tanskanen et al., 2011, p.5). Further, the "tipping point" appears to lead to immediate (mostly emergency) help, possibly due participants' feelings of helplessness (Bogen-Johnston et al., 2019, p.1311), suicidal (and other self-harm) thoughts (Kamens et al., 2018, p.311; Tanskanen et al., 2011, p.4), and being overwhelmed by "dread...the anxiety" (Macnaughton et al., 2015, p.295). Interestingly, age may have also exacerbated help-seeking at this stage, with one participant reporting:

> *"Well, I've just got older and, and, and my, you know my mental, mental and physical resources aren't, aren't as power- powerful as strong as the used to be" (Bogen-Johnston et al., 2019, p.1311)*

External events and circumstances seemed to play a significant role at this stage: participants' peers receiving effective help appeared to be a motivator to seeking help (Macnaughton et al., 2015, p.295). Police arrests appeared to help some (Ferrari et al., 2018, p.359; Kamens et al., 2018, p.311; Melton et al., 2020, p.1125), but it also increased fear of services for ethnic minority participants (Singh et al., 2013, p.40).

While most authors discussed the "tipping point" as ending at service and medical intervention, participants appeared to describe it as an ongoing process that involved a reframing of past experiences and adopting a biomedical one, which may or may not have been considered beneficial by the participant. One described described it as such:

> *"I came to know it was delusions. Every time I came to believe God was closer, I worry that I might have a delusion again. It's hard to believe in God the right way, without the delusion. Little by little my faith became destroyed . . . I don't have my self." (Judge et al., 2008, p.98)*

Healthcare providers may have found it necessary for participants to adopt and use a medical framework over participants' explanatory frameworks; however, the latter may have been more representative of their culture, beliefs, and individual differences. This could have inadvertently undermined their faith, their sense of self, and their ability to connect to their cultural, social, and familial systems (Judge et al, 2008, p.98; Macnaughton et al., 2015, p.296). As a result, some participants reported creating a “blend [of] their earlier interpretive frames (e.g., spirituality, limit identities, etc.) with the notion of illness” (Macnaughton et al., 2015, p.296), while others did not but wanted to “[find] meaning in the illness experience” (Judge al., 2008, p.98; Nordgaard et al., 2020, p.10). With that in mind, the role of healthcare providers in recovery styles remained unclear; across the studies it showed that some supported individuals in developing their own understanding of FEP, while others emphasized a medical interpretation over participants’ personal beliefs, values, and interpretations (Cabassa et al., 2018; Judge al., 2008, p.98; Nordgaard et al., 2020, p.10; Singh et al., 2013, p.41; Tansakenen et al., 2011, p.7).

4. Discussion

The aim of the meta-ethnography was to understand the facilitators and barriers of help-seeking from the perspectives of participants that have experienced FEP.

4.1. Summary of the findings

The research included in this synthesis suggests a chronological process in the noticing, sense-making, and help-seeking experiences associated with FEP. Participants described that as FEP begins to emerge, it is contextualized and/or normalized, with psychotic-like experiences being attributed to other psychosocial events or stressors. As FEP intensifies, participants became more uncertain of their initial attributions about these changes, leading to explanatory frameworks to accommodate any contradictory experiences or beliefs. These frameworks supported participants' sense-making and were associated with either delaying or facilitating help-seeking. Participants also reported that as FEP progressed, significant others noticed these changes and had a significant role in either preventing or promoting help-seeking.

Help-seeking also appeared to depend on interpersonal factors for participants, such as in the relational, cultural, ethnic, and systemic dynamics within the familial and social network. Some reported disclosing to friends first, parents first, or chose not to disclose at all due to concerns of other people's perceptions. Similarly, the perceived quality of care of services and entry pathways also appeared to play a role in delaying or facilitating help-seeking for participants. If participants did not seek or receive help either during the beginning of FEP or from services, friends, and/or family, most would experience a "tipping point", leading to an immediate response either by the participants themselves, their family, or services. This resulted in newer, often more medical interpretations of their FEP experiences, which could be helpful or unhelpful depending on their sense of self and ability to reassimilate to their social, cultural, and familial systems.

4.2. Clinical and research implications

The staged-like process and relationship between FEP and help-seeking carries interesting and significant clinical and research implications.

4.2.1. Delaying help-seeking due to misattributions, contextualizing, and/or normalizing

A delay in help-seeking due to misattributing FEP experiences to other stressors was a common occurrence amongst participants, particularly in their reporting that they initially believed these experiences to be from psychosocial stressors, such as depression. There does appear to be a relationship between mood and psychosis (Kiran & Chaudhury, 2016; Häfner, 2010), with longitudinal studies reporting that depression can predate FEP or psychotic relapse (Morales-Muñoz et al., 2021). Moreover, mediators associated with distress in psychosis tend to include depression (Bentall et al., 2009; Hartley et al., 2013). This suggests that, although these misattributions may have led to delays in help-seeking, it is possible that depression or other mental health-related difficulties were happening concurrently, influencing one another, or maintaining the psychosis.

Throughout each stage, participants reported struggling to attribute their experiences to a psychosis, but they also described a process of trying to understand it. This struggle could be due to metacognitive difficulties, which is theorized to occur in people who experience psychosis and their sense-making processes is negatively impacted. Estroff (1991) theorizes that these processes, like contextualizing and normalizing, emerge when people are trying to make sense their experiences, which can be helpful but can also result in them assimilating experiences to their identity. Coupled with metacognitive difficulties, these processes may have delayed help-seeking if participants' attempts to make sense of their experiences led to interpreting them as "normal." While the underlying mechanisms that are occurring at this stage of FEP remain unclear in both our findings and in current research, our results suggest that delays in help-seeking at the early stages of FEP may be influenced by several factors, such as misattributions, contextualization, and normalization, rather than just a lack of insight (Horgan & Sweeney, 2010).

4.2.2. Delaying help-seeking due to growing feelings of uncertainty

Having a sense of uncertainty about FEP appeared to delay help-seeking for participants. One explanation could be metacognitive difficulties, as some can enter a "hyper-mentalizing mode" (Abu-Akel, 1999) where they have several ideas of what may be occurring without a single idea appearing more likely than the other. It may also be due to feelings of threat (Sarason, 2019); a sense of uncertainty can be particularly disruptive and may lead to maladaptive responses such as avoidance, heightened reactivity, and hypervigilance (Grupe & Nitschke, 2013) – all which participants described. Many participants responded to the uncertainty by modifying their own behavior rather than help-seeking. While research is scarce on this topic, Coffey and Hewitt (2008) posited that these kinds of responses to uncertainty may happen when the type of help available is either not what they are seeking or seems threatening, either due to stigma or past negative experiences with them. We do not know if this was true for our participants, as it was difficult for them to articulate their sense of uncertainty and how it affected their behaviors.

4.2.3. Facilitating and delaying help-seeking due to explanatory frameworks

The relationship between explanatory frameworks and help-seeking in our findings was unclear, showing it can both facilitate and delay help-seeking. When looking at qualitative studies that explored explanatory frameworks in depth, spiritual and religious frameworks have been found to be particularly influential frameworks for coping and meaning-making (Chio et al., 2008; Milner et al., 2019; Niu et al., 2021). For example, Yang and colleagues (2012) explored long-term hospitalization in Taiwan and found that religious and spiritual frameworks were predominantly used to explain and cope with various features of distress. While this is similar to our synthesis, ours also showed that, other than being a way for participants to cope and make sense of their experiences, it also influenced their help-seeking depending on the ethnicity, culture, values, and beliefs of our participants.

The other common explanatory framework found was being a victim or persecuted; for some participants this facilitated help-seeking, believing they were in danger. Some argue this framework in particular arises from pre-existing potential difficulties, such as anxiety and depression (Dominguez et al., 2011; Fowler et al., 2012), paranoia (Morrison et al., 2015), metacognitive difficulties (Lysaker et al., 2014), or an "insecurely constructed self" (Trower & Chadwick, 1995) that is externalizing the "bad" aspects of themselves. What this means for help-seeking has been contradictory in both our synthesis and the literature, with some suggesting this framework can delay help-seeking due to the maintaining factors of persecutory beliefs, the person's identity, and their self-esteem (Fornells-Ambrojo & Garety, 2009; Melo & Bentall, 2012; Tiernan et al., 2014) while others found that it generally does not impact clinical outcome (Huguelet et al., 2010).

4.2.4. The role of significant others on facilitating and delaying help-seeking

Helpful involvement from significant others led to help-seeking for participants and less helpful involvement led to delays. Several studies have demonstrated the role of others in facilitating or delaying participants seeking help (Anderson et al., 2012; Castelein et al., 2015; Compton et al., 2008; Connor et al., 2014; Fridgen et al., 2012; Marchira et al., 2012; Odeyemi et al., 2018; Odinka et al., 2014; Weiss et al., 2021). Moreover, the finding that stigma delays help-seeking in our participants is a well-documented finding, with a recent meta-analysis showing significant correlations between age, sex, education, culture, and stigma (Eliasson et al., 2021), as well stigma having a damaging effect on discrimination experiences at cultural, systemic, and interpersonal levels – all which participants described as potential fears or consequences to help-seeking.

An interesting finding was peer support and the different ways it facilitated help-seeking for participants. While one may assume that peer support is mostly delegated to being a supportive social network, we also saw participants seeking help after witnessing their peers receive effective help (Macnaughton et al., 2015, p.295), and that disclosure sometimes began with peers to gauge reactions prior to family members; also known as "conditional disclosure" (Gronholm et al., 2016). Research on peer support shows that not only can loss of social support predate the onset of psychosis and delay help-seeking, but that friends, family, and romantic partners reported to have been affected by psychosis, too, as it made it more difficult to maintain a strong connection (Harrop et al., 2014. However, efforts to implement peer support as an intervention by mental health services have thus far been inconsistent and complicated (Davidson et al., 2012), and a 2013 meta-synthesis by Walker and Bryant found that peer support workers often reported low pay and prejudice from other staff.

4.2.5. The role of services in help-seeking

Our results suggest that helpful involvement from services facilitated help-seeking while less helpful involvement led to delays. Participants described staff friendliness, active listening, collaboration and exploring options to have facilitated help-seeking. This aligns with a "recovery-oriented" service which adopts a perspective that not only are service-users capable and resourceful, but that they should promote a reconstruction of the dynamic between service, healthcare provider, and service-user (Slade et al., 2014). However, participants also reported negative interactions with services that delayed help-seeking, which is also reflected in the wider literature. In a mixed-methods study by Cully and colleagues (2020), they found that a significant portion of their participants had a negative experience engaging with services, reporting an over-reliance on medication, inconsistences in personnel, insufficient follow-up, and lack of empathy. This, along with our findings, suggest the relationships between service-user and service has a powerful impact on decisions made when deciding to seek help, as well as adherence to medication and disengagement from services. Thus far, efforts to change this have been especially difficult in regard to services having the time, resources and training to develop, implement, and evaluate effective organizational models to recovery-oriented practices (Ocloo & Mathews, 2016).

It is usually when participants reached the "tipping point" that they received immediate help, which is one of the most reported pathways to help-seeking for FEP (Armijo et al., 2013). Our findings also showed that for some participants, once they sought help it was difficult to adopt medical frameworks to make sense of their FEP, as the ones they generated were mostly based on their beliefs, cultures, and values; they preferred a blend between medical and their own framework. This is not uncommon and there have been debates around the appropriateness of a medical framework, for it can imply that clinicians are better at making sense of a person's experiences than the person themselves (Johnstone & Boyle, 2018). Using the "Recovery Styles" concept (McGlashan, 1975), an "integrated" recovery style could allow service-users, once they sought help, to explore the meaning psychotic experiences have for them and consider how it emerged in a way that would increase their trust and engagement with services.

Negative relationships between service and service-user appear to be further compounded in regard to ethnic, gender, power, and individual differences. For example, participants from minority ethnic backgrounds commented on mistrust towards services based on negative interactions they have had with them in the past. This is supported by reports of ethnic minorities describing similar challenges when seeking care (Cook et al., 2013; Ghali et al., 2018; Lee et al., 2014; Picco et al., 2016). Participants also reported delaying help-seeking due to concerns of their treatment of care based on their ethnicity; it has been reported that services find it difficult to improve equity and relationships in mental health care across races and ethnic groups whilst also attending and tailoring to cultural differences (Breslau et al., 2017). This continues to remain a challenge in services (Shim, 2021), and current research is exploring barriers to advancing mental health equity (Graham et al., 2021; O'Keefe et al., 2021; Ramos et al., 2021). This is a complicated subject to address as equality, diversity, and inclusion training has not always translated well in practice or made significant change to people's attitudes, beliefs, or treatment of others, regardless if service-users presented with FEP or not (Dobbin & Kalev, 2018).

4.3. Recommendations

4.3.1. *Making individual voices heard*

Given the challenges in advancing mental health equity, it is important for both qualitative and quantitative research to explore individual and ethnic differences in regard to how psychosis is made sense of, explanatory models that are generated as a result, and the relationships developed with services and their familial and social network. This may improve our understanding to pathways of care for psychosis and clarify how some factors, such as explanatory models, can both facilitate and delay help-seeking.

4.3.2. Psychotherapeutic approaches within services

Making sense of FEP was shown to be important both prior to seeking help from a service and afterwards, and work is needed to understand how it can be best addressed within services. With psychotherapeutic interventions for voice-hearing, it may be beneficial to include interventions such as meta-cognition (Dimaggio & Lysaker, 2010), narrative insight, and rapport-building, as research has demonstrated improved outcomes (Bröcker et al., 2020; Eichner & Berna, 2016; Lopez-Morinigo et al., 2020; Moritz et al., 2019; Rosenbaum et al., 2012). However, more evidence-based research is needed in how this could be implemented for people with psychosis before seeking help from a service, during, and after discharge. There is also a need to clarify the relationship between psychosocial stressors and psychosis due to participants' initial misattributions of FEP; there have been correlational studies conducted, however more research is needed to understand if these are co-occurring, are a result of one another, or something else entirely. This could help healthcare providers better identify FEP given that psychosis tends to emerge subtly and overlaps with experiences like depression.

4.3.3. The relational roles between service and service-user

In a systematic review by Eassom and colleagues (2014), they argue that for involvement from significant others to be effective, there needs to be training for healthcare providers on flexibly accommodating both family and individual needs. Therefore, more qualitative and quantitative research is needed to explore how organizational and cultural changes can be made in a realistic way for helpful involvement to happen consistently. This can include exploring recovery styles that integrate service-user's personal beliefs, such as their spirituality and culture. Further, more attention should be paid in how we monitor people's recovery styles that frequently co-occur with psychosis, as it appeared to have a large impact on how they perceived their quality of care.

4.4. Evaluating the meta-ethnography

This meta-ethnography was evaluated for strengths and limitations using the same 19-item checklist under "quality appraisal."

4.4.1. Limitations

Epistemological positions of the primary studies were often unclear, potentially losing valuable information on authors' influences, biases, and reporting of data. Further, while the author of this meta-ethnography provided definitions for psychosis, FEP, and help-seeking, most studies under review did not, which could have been important when exploring how authors made sense of participants' experiences. Meta-ethnographies are also interpretive and involve translating studies to one another, which results in interpretations being influenced by the authors own individual, cultural and historical factors. For example, it was difficult to extract meaningful information about ethnic and individual differences across studies, unless this was already an aim of the authors. Further, sociodemographic information was mostly used to report descriptive rather than interpretive differences. Therefore, it was not possible to sufficiently extrapolate individual differences based on gender and culture, two of which were highlighted as influential to help-seeking.

The present author initially felt concerned about missing potentially important individual differences between participants when translating and synthesizing studies, which was important given that the author is female and identifies as BAME. Discussions were had in supervision to reflect on this and implement strategies to advance and progress the meta-ethnography. Finally, meta-ethnographies are an evolving approach and there is a current lack of clarity and comprehensiveness around the reporting of methods, analyses, and synthesis, which was found to be challenging during phases “determining how the studies are related”, “translating the studies into one another”, and “synthesizing translations”. As such, rigor and credibility can be difficult to appraise, highlighting a need for methodological guidance that is tailored to meta-ethnographies.

4.4.2. Strengths

A key strength of this meta-ethnography was that it had a clear approach to investigating the research question at hand and provided definitions for the psychosis concepts that were going be explored. It also used a rigorous research design and methodology to not only demonstrate appropriateness to the research question but justify how data collection, and analyses would be used. As there is little guidance on conducting this for meta-ethnographies, the author consistently met with a wider meta-ethnography support group and used supervision for discussion of this. Although there were participant and study characteristics missing from individual studies, they were appraised and extracted transparently to ensure studies could address the research question. Another strength was a clearly stated epistemological position and the author’s role in this meta-ethnography, as well as the role of her supervisor and meta-ethnography group. In addition, the analyses and findings explored both complementary and contradictory data, with the aim to add to the overall “richness” of the synthesis whilst still being compatible with the research question.

This meta-ethnography attempted to be comprehensive in exploring individual and group differences. The author was aware of her own biases, cultural, and historical influences and utilized reflective discussions with her supervisor who was male and from a White background to help in balancing views. The author also utilized reflexivity throughout the entire meta-ethnography process by keeping a reflective diary, which helped in clarifying her position towards psychosis and help-seeking. This was imperative in being able to demonstrate a holistic and thorough analyses of the findings.

4.5. Conclusions

This meta-ethnography aimed to explore personal accounts of the facilitators and barriers of help-seeking for FEP. 15 primary articles related to this aim were extracted, appraised, and analyzed. Following Noblit & Hare’s (1988) guidance, two levels of analysis were applied to the studies, which resulted in a total of five themes and six subthemes. The findings suggested a chronological process of participants making sense of FEP, which either led to or delayed help-seeking. When help was sought from services, the type of support provided appeared to be influenced by participants’ interpersonal, cultural, individual, and systemic roles.

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Chapter II. Empirical Paper

SPIRITUAL UNDERSTANDINGS OF PSYCHOSIS: THE PERSPECTIVES OF SPIRITUAL CARE STAFF

Abstract

Introduction: Pathologizing spiritual beliefs has been an ongoing challenge in mental health services, especially when clinicians need to discern psychosis-like experiences that present with religious or spiritual content. Thus, spiritual care services have been working alongside clinicians on service-users having psychosis-like presentations, but there has been little to no research on their perspectives or work with psychosis. Therefore, this study aimed to explore how spiritual care staff make sense of experiences otherwise termed as "psychosis" in services.

Method: Using Interpretive Phenomenological Analysis (IPA), a multi-faith sample of six participants were interviewed via a video conferencing software. This consisted of a semi-structured interview and three case vignettes to explore their meaning-making experiences of psychosis, spirituality, religion, mental health services, and spiritual care.

Findings: Participants acknowledged "psychosis" as a label that is applied to certain experiences. These experiences were described as spiritual in nature as it affects a person's overall awareness, quality of life, wellbeing, and overlaps with co-occurring psychological, environmental, and biological factors. Therefore, holistic working is emphasized; depending on service-users' needs, participants used validation, empathy, acceptance of service-users' explanatory frameworks, support for medical involvement, and religious resources (e.g., prayer). Mental health services were described as being more acknowledging of spirituality, but still predominantly biomedical, with some staff underutilizing spiritual care in psychosis recovery despite service-users finding it helpful and supportive.

Discussion: Integrating spiritual care within the work of existing mental health services requires ongoing conceptual and practical considerations, including spiritual care education, training, and collaboration.

5. Introduction

Psychosis occurs across several psychiatric, neurological, developmental, and medical difficulties, making it important for services to assess, evaluate, and provide suitable support for (Arciniegas, 2015). As most services are encouraged to adopt a biopsychosocial framework (Kusnanto et al., 2018), they generally make sense of psychosis by using, but not limited to, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) and the International Classification of Diseases, Eleventh Revision (ICD-11). These define psychosis as generally presenting with hearing voices ("auditory hallucinations"), visual hallucinations, odd beliefs ("delusions"), and a lack of self-awareness or "insight". These characteristics or "symptoms" are also believed to occur along a spectrum from mild to severe, is affected by social and environmental factors, and is associated with cognitive and emotional disturbances (Arciniegas, 2015; Arnedo et al., 2015; Linscott & Van Os, 2013).

It is not uncommon for clinicians to use a biomedical approach for psychosis as opposed to others that may be more person-centered, such as a transdiagnostic approach (Kusnanto et al., 2018; Raffay et al., 2016). Given the psychosis spectrum, it can present differently from person to person (McCarthy-Jones et al., 2013), and a biomedical approach may be one way to narrow down a diagnosis. However, studies show that not all people presenting to services with psychosis find this approach helpful (particularly from minority backgrounds), and instead want more tailored, culturally appropriate, and compassionate care (Hefti, 2011; Islam et al., 2015; Weich et al., 2012). Aside from more family and community involvement in their care (Farrelly et al., 2014), people with psychosis reported wanting opportunities to share how their spirituality and religion influences or affects their psychosis without it being pathologized by healthcare providers (Marriott et al., 2018; Milner et al., 2019; Pelechova, Wiscarson, & Tracy, 2012).

5.1. Services working with psychosis

In mental health services in western countries, particularly the United Kingdom (UK) where the biomedical and diagnostic categories predominate (Caspi et al., 2020; Pitt et al., 2009), service-users experiencing psychosis may be deemed as lacking insight if they articulate or explain their psychosis in a way that differs from conventional diagnostic categories (Marriott et al., 2018). This is one of the reasons why there is a current debate around the appropriateness of psychiatric diagnoses for presentations like psychosis (British Psychological Society [BPS], 2013; Johnstone & Boyle, 2018). This, along with the aforementioned dissatisfaction with the biomedical approach from service-users, has led to several proposals for services to implement approaches that accommodates both service-users' needs and their personal meaning-making as part of their care (Atapattu et al., 2022; Boardman & Shepherd, 2012; Jacob et al., 2015; Lysaker et al., 2009; Noiseux et al., 2009; Skar-Fröding et al., 2021; Tranulis et al., 2009). Further, the UK's government strategy "No health without mental health" (2011) called for healthcare practitioners to focus less on psychotic symptom reduction and more on recovery-oriented approaches that integrate service-users' relationships, education, and "purpose". Given reports of "spirituality" missing from services, one such integration has been the inclusion of spiritual care services (Milner et al., 2019; Raffay, 2016; Saleem et al., 2012).

5.2. Spirituality, psychosis, and spiritual care services

Spirituality can be generally understood to mean having personal practices that increase one's sense of meaning, connection, and purpose (Gilbert & Parkes, 2011; Milner et al., 2019). Psychosis and spirituality appear to frequently intersect and act as a mediator in psychosis recovery (Marriott et al., 2018; Tuttle et al., 2019). If people with psychosis are experiencing it with a religious or spiritual presentation, many prefer to seek help from faith healers first before mental health services, which can either lead to or delay help-seeking (Dein et al., 2012; Islam et al., 2015; Menezes & Moreira-Almeida, 2010; Suhail & Ghauri, 2010). This has led to a growing call of including spiritual care services in mental health services (Leavey, 2010; Friedli, 2000; Ministry of Housing, Communities, and Local Government, 2018; Wood & Alsawy, 2017), with studies showing that people with psychosis particularly enjoyed working with spiritual and religious leaders, as they would take a non-pathologizing approach to their beliefs (Hagen & Nixon, 2010). Moreover, a qualitative systematic review by Milner and colleagues (2019) found that even when spiritual and religious needs were considered "vital" by service-users, they were often not integrated, as mental health services and healthcare providers expressed lacking the confidence to thoughtfully integrate the spiritual aspect into someone's care. This is what is referred to as the "religiosity gap" in mental health services (Van Nieuw Amerongen-Meeuse et al., 2018).

The "religiosity gap" in care can be challenging for both service-users and healthcare providers; service-users may not be asked by clinicians about their beliefs and how it affects their experiences, potentially excluding it from their care altogether (Dein et al., 2012). At the same time, clinicians may find it difficult to distinguish between psychological disturbances, such as an acute psychotic episode, and experiences that are aligned and consistent with service-users' spiritual, cultural, or religious beliefs (Arnaud & Cormier, 2017; Menezes & Moreira-Almeida, 2010; Spittles, 2020). Further, there is a significant underevaluation of spirituality factors in psychosis recovery in mental health assessments and outcome measures (Grover et al., 2014; Heffernan et al., 2016; Menezes & Moreira-Almeida, 2010; Milner et al., 2019), continuous pathologizing of spiritual beliefs as mental illness (Mooney, 2009), and little research that includes perspectives on psychosis from spiritual care services and staff (Cook, 2013). As such, the World Health Organization (WHO) and UK National Health Service (NHS) have emphasized spiritual care within healthcare services as essential to integrate (Sinha & Kumar, 2014; Barber & Parkes, 2015), in particular the consideration of alternative frameworks (aside from the biomedical view) and the promotion of more positive service provider-service-user relationships, particularly with ethnic minorities (Spittles, 2020; Weber & Pargament, 2014).

Currently, the spiritual and pastoral care services in mental health services can work with people experiencing psychosis in a variety of ways, such as building resilience, increasing their sense of connection, and promoting recovery and hope (Forrester-Jones et al., 2017; Heffernan et al., 2016; Phillips et al., 2009). These services are usually made up of a group of staff, such as faith leaders, who integrate spirituality and/or religion in a way that enhances people's overall wellbeing (Koenig, 2014). Service-users thus far have found the integration beneficial to their recovery (Koslander & Arvidsson, 2007; Leavey, 2008; Rashid et al., 2012). With that in mind, a 2016 study by Raffay and colleagues in the UK found that, although participants benefited from chaplaincy involvement, spiritual care services were not used widely enough as part of patient care. This indicates a need for further exploration on spiritual care services and their perspectives and work with psychosis.

5.3. Rationale and aims

As spiritual care services are included in multidisciplinary mental health services, there is an opportunity to develop our knowledge around how staff in spiritual services understand and work with people experiencing psychosis. Therefore, this study aimed to explore the following question:

How do spiritual care staff understand their work with service-users who experience "psychosis[2]"?

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[2] Terms such as "psychosis" and its associated diagnostic definitions are currently being contested and debated on its appropriateness, cultural relevance, and suitability. For the purposes of convenience for this study, experiences that involve hearing voices, perceptions, or beliefs that others may consider "delusional" or "odd" will be classified as either "psychosis", "psychosis-like experiences", or "people with psychosis". This should not imply a biomedical causal understanding of psychosis.

6. Methodology

6.1. Epistemological and spiritual position

The author of this study adopted a combination of a relativist epistemology and realist ontology, otherwise known as a critical realist stance (Bhaskar, 2013; Pilgrim, 2019). This stance acknowledges that not everyone that experiences or works with psychosis makes sense of it in the same way (Cooke, 2020). It also acknowledges that statements about either psychosis or working with psychosis is based on perspectives in a socially constructed world. As such, statements by participants will be treated as perspectives rather than objective facts.

The author has a strong spiritual interest in psycho-spirituality, Sufism, folklore, and cultural superstitions about the supernatural. Therefore for this study, the author took an *agnostic* position in order to bracket her own beliefs, biases, and attitudes to ensure participants' perspectives are conveyed in a conscientious and thorough manner.

6.2. Ethical Approval

The study complied with all necessary ethical and regulatory frameworks (See approval letters in Appendix H). It received ethical approval from the University of Birmingham and was organized through the National Health Service's (NHS) Health Research Authority (HRA), as participants were staff working in the NHS. The process of ethical approval included ensuring informed consent (including confidentiality, anonymity, and withdrawal), data collection methods, data management and storage, and prevention of harm to participants were appropriately and suitably considered and implemented.

6.3. Design

The method of this study was qualitative, given the need for more in-depth and explorative research on spiritual care services and their work with psychosis. As such, two data collection methods were used: a semi-structured interview and three case vignettes. These methods were chosen to facilitate a detailed, explorative interview with case vignettes used as part of illuminating meaning-making experiences of spiritual care and psychosis. The semi-structured interview consisted of pre-written interview questions and topic guides (Appendix L). The case vignettes were written by the researcher and aimed to reflect some of the most common psychospiritual psychosis difficulties that can present in services.

The design was Interpretive Phenomenological Analysis (IPA) (Smith et al., 2009). IPA was chosen as its dynamic processes allows for rich and nuanced explorations of potentially complex or ambiguous topics, such as spirituality, whilst also examining meaning-making and subjective experiences, namely spiritual care, mental health services, and psychosis (Smith & Osborn, 2015). Also, IPA's "homogenous sampling" allowed for a multi-faith sample to be used, which was favorable given most empirical studies on spirituality have been on single-faith samples (Larkin et al., 2019; Weber & Pargament, 2014).

6.4. Setting

Due to COVID-19's research restrictions, interviews took place online using a secure video-conferencing software.

6.5. Participants

6.5.1. *Recruitment*

It is typical for IPA sample sizes to be small (Smith et al., 2009). To have homogeny for this study, a sample of four to 10 participants was aimed for, which is the recommended sample size for professional doctorates (Smith, 2004).

Recruitment took place between February and March 2022. A non-randomized convenience sampling method was employed: an email consisting of a brief outline of the research aims (Appendix I**)**, participant information sheet (Appendix J), participant consent sheet (Appendix K), and contact details of the researcher was emailed to the manager of Spiritual Care in a West Midlands UK mental health service. The manager forwarded the email to her staff of spiritual care staff and chaplains[3]. Interested potential participants contacted the researcher on her secure email address and a date and time would be arranged to conduct the interview. An invitation link to the agreed interview date was sent after a signed consent sheet was obtained by the researcher. Participants would have had to have met the following inclusion criteria (Table 7):

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[3] The term “chaplains”, “chaplaincy”, “chaplaincy work”, and “chaplaincy services” is used in this study interchangeably with faith leaders, spiritual care, and spiritual care services because both the participants and the manager of the spiritual care service also used those terms interchangeably when discussing the type of work and service they provide.

Table 7.

Inclusion and Exclusion criteria.

Inclusion Criteria	**Exclusion criteria**	**Rationale**
Faith leaders, spiritual practitioners, chaplains	Spiritual/faith practitioners and chaplains in training	The study aimed to find participants that have already had experiences and perspectives working with psychosis.
Over the age of 18	Under the age of 18	The study aimed to recruit people employed as spiritual care staff (i.e., will be working age).
Based in the UK	Not based in the UK	The study was interested in exploring working with psychosis in a UK mental health service.
Access to the internet	No access to the internet	Data collection was conducted entirely online.
Fluent in English	Requires an interpreter	Due to the limitations of research sponsorship for this study, there were no resources available to support the

		recruitment of an individual who did not speak fluent English.
Voluntary participation	Practitioners that charged fees for spiritual/faith/religious consultancy	The study did not provide monetary or otherwise benefits for participating.

6.5.2. Sample

Eight potential participants emailed the researcher expressing their interest. Six were included in this study, two were excluded. The reason for exclusion was because they never responded when asked for an available interview date.

This sample consisted of two females and four males: two Muslim Imams, one Roman Catholic Deacon, one Pagan Priestess, one Christian chaplain, and one Pentecostal Christian Chaplain. The age range was between 42 – 68 years. To maintain participant anonymity, specific ages and faiths of participants were not directly expressed or associated to any one participant.

6.6. Data collection method

6.6.1. *Procedure*

Participants met the researcher on a secure video-conferencing software and an encrypted and password-protected Dictaphone was used to audio-record the interview. The shortest interview lasted 55 minutes and the longest 95, for an average of 71 minutes. Participants were only interviewed once. After the interview, the researcher stopped recording and debriefed the participants using a debriefing script (Appendix O). No participants withdrew from the study. Continuous consent was used throughout in anticipation of delving into unanticipated areas and subjects. Capacity was also assumed unless there was additional information to indicate otherwise. The researcher then transcribed the interviews, anonymizing identifiable details where possible (e.g., using different names or redacting service locations mentioned).

6.7. Data analysis

Each transcription underwent IPA analysis. The process of IPA analysis had two aims: first, gather how participants understood their work with people experiencing psychosis, identifying the phenomenological concerns of the participants and their claims about it. This was done to produce an informed description that was as "close to the participants' view as possible" (Larkin et al., 2006). The second aim was to develop a more interpretive analysis by relating this informed description to a wider, social, and/or cultural context. This helped provide more conceptual understandings of how participants make sense of and work with psychosis-like experiences (Smith et al., 2009).

The table below illustrates the step-by-step process of how IPA was used for this study. An example of one of the participant's ("Wilma") (Appendix M) is demonstrated to further highlight the process.

Table 8.

The steps taken to carry out an IPA analysis.

IPA Steps	Rationale (in accordance with Smith et al., 2009)	An example: "Wilma"
Reading and re-reading	Each transcript to be read several times to begin the process of understanding participant narratives	Interview was re-read throughout the transcribing process. Once completed, it was continuously re-read over several days to immerse the researcher into the data.
Initial noting	Each transcript to be explored in-depth: the semantic content, language, contents, and concepts used	The author generated a three-column table: "Interpreted themes", "Original Transcript", and "Exploratory comments". Under "Exploratory comments" the researcher explored the content, language, metaphors, and concepts used in transcript "Wilma", as well as her own reflections.

Developing emerging themes	To begin generating interpreted themes for each transcription that reflect individual participant narratives and the researcher's interpretations	Using the same three-column table, under "Interpreted themes" the author wrote down the interpreted themes of "Wilma" line-by-line, which was also guided by the notations made under "Exploratory comments".
Searching for connections across emergent themes	To generate interpreted themes across transcriptions that reflect both individual and collective participant narratives, as well as the researcher's interpretations	"Interpreted themes" of each transcript were compared and explored both to gain an overall descriptive summary of participants' narratives, as well as to make interpretations of participants experiences, narratives and reflections.
Identifying quotes to illustrate themes	To make clear connections between each theme and participant.	Quotes from transcripts were printed out and physically charted until we reached clear interpreted

	themes with distinct voices (Appendix N)

6.7.1. Reflexivity and monitoring quality in the analysis

To monitor research quality for IPA, the researcher followed the guidance of Nizza and colleagues (2021), as it contained the most comprehensive guide on implementing and assessing IPA criteria by using four “quality indicators” that contribute to a study’s trustworthiness, adherence to IPA principles, transparency, coherence, and richness. This was applied to each theme, sub-theme, quotes used, and any analytic commentary by the researcher. The table below illustrates this process (Table 9).

Alongside this, the researcher kept a reflective diary. As the researcher is a North African-Arab female in her early 30s with an interest in both psychosis research and spirituality, the diary was used to track her emotions, beliefs, attitudes, and biases to psychosis, spirituality, and mental health services. The researcher also reviewed the quality, rigor, transparency, and trustworthiness of her findings with both her supervisor and a qualitative analysis support group, which consisted of doctoral trainees and qualified research supervisors.

Table 9.

Quality indicators as guided by Nizza and colleagues (2021).

Quality Indicators	**Rationale (as provided by Nizza et al., 2021)**	**How this was applied to this study**
Constructing a compelling and unfolding narrative	Findings should convey a "narrative" that is not only coherent to the analysis but expresses the hermeneutic circle that links to how the researcher understood the findings as a whole.	Each quote was used to contribute to the narrative of the overall findings. Analytic commentary by the researcher about these quotes were aimed to not only add to data richness, but be interconnected, accessible, and easy to follow.
Developing a vigorous experiential and/or existential account	The quality of the analysis is increased depending on the depth and insight it can offer, which is the primary of aim of phenomenological inquiry in exploring lived experiences.	Data was explored in-depth: what "psychosis" means to participants, how participants work with it, where experiences differ and/or complement the other, and how the findings generate reflective activity by participants.

Close analytic reading of participant's words	IPA follows Heidegger's (1962) hermeneutic phenomenology, which considers phenomenological enquiry as inherently interpretive. This makes IPA a double hermeneutic challenge: participants make their own interpretations and meanings of their world, and the researcher interprets their interpretations (Smith & Osborn, 2008).	Ensured steps in Table 8 were followed so data could be grounded in its trustworthiness, used a reflective diary, and reviewed the quality, rigor, transparency, and trustworthiness of the researcher's findings with both her supervisor and a qualitative analysis support group.
Attending to convergence and divergence	IPA aims for an idiographic analysis where each case is examined on an individual and detailed level. Therefore, small purposeful samples are valued.	The sample used was accessed purposefully to ensure participants were able to engage fully with the interview and case vignettes as part of illuminating their experiential world and associated sense-making. Each case was compared to identify similarities and differences with particular attention paid to nuanced interconnections between and across experiences.

7. Findings

The following table consists of the three case vignettes that were provided to each participant. These are referenced throughout the findings.

Table 10.

Case Vignettes that were presented to participants.

Name	**Vignettes**
Hannah (Vignette A)	Hannah is a 31-year-old woman who works as an Accountant part-time. For the last 2 weeks she has not been coming into work. A few months ago, she was talking to her husband about seeing faces and shadows on the walls and hearing someone whisper her name. She once tried to record it on her phone but found she could not and told her husband she was afraid of "going mad." Hannah told her husband she did not know what this was and felt afraid. Since quitting her job, Hannah has grown more aloof and detached, often avoiding talking to her family. Her husband stated that she can also suddenly become argumentative and aggressive for no apparent reason. Sometimes her husband hears her talking to herself when nobody is around. She has also been refusing to eat and has explained that she suspects the neighbors are poisoning her food. When speaking with Hannah, she says that she thinks someone – possibly the neighbours – has "cursed" her and she is now being "tormented" by evil spirits. Hannah does not feel much hope about her future and believes she must have done something wrong in order for her neighbours to have cursed her. She has had some suicidal thoughts but has never tried to harm herself. Hannah is attending spiritual care as she would like help to remove the curse.

Nadeen (Vignette B)	Nadeen is a 25-year-old teacher who was very close to her father before he passed away from a terminal illness with a life expectancy of just a few short months. Before her father passed, he told her that they would remain in contact after death. According to Nadeen's husband, she went through a complicated mourning period when her father died, as she first was completely devastated before becoming more cheerful and more interested in returning back to work about 6 months later. Curious about the dramatic shift, her husband began observing her around the house and noticed that she was talking to herself in their bedroom at least once a day for an hour each time. When he asked who she was talking to, she told him that her father likes to visit her once a day to see how she is doing. Aside from that, he has not noticed any deterioration in her mental health or her personality worthy of note, but he has asked her to visit a service to talk about this. She told him that talking to her father makes her happy and keeps her life normal and balanced. They both disagree about the source of this experience and it is causing frequent arguments between them. Nadeen has attended spiritual care as she wants her husband to understand that she finds the visits from her father's spirit comforting, and she is happy that these continue for as long as her father wishes to visit.
Jimmy (Vignette C)	Jimmy is a 28-year-old Master's student who was diagnosed with schizoaffective disorder when he was 25 years old after hearing voices that told him he was evil and was going to suffer, as well as believing that he is being used as a vessel by a demon to purge the world of evil. Terrified, Jimmy joined a spiritual/religious support group and spent most of his savings with the religious group in an effort to manage the

> unpleasant experiences. However, Jimmy's thoughts grew worse, so he eventually sought psychiatric support, following which he was he was diagnosed and started on treatment for psychosis. Since then, Jimmy has stopped believing in any higher power and said he feels bittersweet about the entire experience and diagnosis. He now feels he can attribute all of these experiences to the diagnosis and can orient himself better to reality. However, his medication needs to be changed and Jimmy is worried that the voices may return to try to convince him that they are "real". Jimmy is visiting spiritual care to see if they can offer any help with these worries and stop him "slipping back".

This following table provides a summary and overview of the findings. Each subtheme is discussed within the broader theme and the participants that contributed to each subtheme is made clear and distinct. This was part of developing an understanding of how participants conceptualized and understood their work with people with "psychosis".

Table 11.

Summary table of themes.

Theme	***Subtheme***	***Participants contributing***
7.1 Spirituality transcends and connects the individual	*We are one entity, and things are intertwined*	*Jason, Jerrod, Kareem, Nadiyah, Wilma*
	Science as a part of spirituality	*Nadiyah, Wilma, Mick, Kareem*

	The negative aspects of spiritual experiences	*Wilma, Jerrod, Nadiyah, Mick, Jason*
7.2 Locating “psychosis” within a wider context beyond only the individual	*The importance of understanding the potential harm of psychosis*	*Wilma, Jason, Mick, Jerrod, Kareem, Nadiyah*
	Psychosis can sometimes be a mental health issue (but other times not)	*Wilma, Mick, Kareem, Nadiyah, Jason, Jerrod*
7.3 Chaplaincy as a holistic and bespoke approach to recovery from psychosis	*Providing a holistic care package*	*Kareem, Wilma, Jason, Jerrod*
	Using religious and non-religious activities as a part of tailored spiritual care	*Mick, Nadiyah, Jason, Kareem, Jerrod*
	Working with the views that people bring	*Kareem, Wilma, Mick, Jerrod, Nadiyah, Jason*

	Chaplaincy work is “not a magic wand”	*Mick, Jerrod, Wilma, Kareem, Jason*
	Challenges in implementing chaplaincy work within services that emphasize a medical framework	*Mick, Jerrod, Jason, Wilma, Kareem, Jason*

7.1. Theme I: Spirituality transcends and connects the individual

All participants acknowledged “psychosis” as a label applied to certain experiences, all which occur within a framework of spirituality. What this spirituality framework consists of was described by all six participants in similar, yet broad terms: an “awareness” (Jason; line 171) a person has when trying to understand their experiences, environment, and themselves. As such, participants understood psychosis as a spiritual experience, characterizing people experiencing psychosis as often trying to make sense of what is happening to them and around them.

This was not to be confused with religion; participants stated that religion is a part of spirituality but contains specific “practices and rituals” (Kareem; p.6, line 254). Spirituality on the other hand is a “generality” (Mick; line 38) that can accommodate various experiences and beliefs, like psychosis. Due to spirituality’s broad definition, “lots of people can fall into [this] category” (Mick; line 173/4), which can make it difficult to discern psychosis-like experiences from others. Jason, however, argued that that is precisely why this framework is important, as it can yield a better understanding of how experiences can be affecting several areas of a person's life:

> *"Because my experiences is that sometimes people who are deemed to have experienced psychosis, that can be an aspect of what of what they are experiencing that that is mental. But that can be an aspect that is tied up in their spirituality….I think the danger is, is that the spiritual aspects, just gets missed, because because sometimes, medical practitioners don't understand how deeply embedded people's spiritual thought and spiritual framework is within their whole being" (line 208 – 213)*

Here we see Jason describe potential pitfalls that may occur if psychosis-like experiences are only made sense through discrete frameworks, such as medical-only. He also emphasizes the importance of exploring how psychosis can intertwine with other aspects to the person, such as their sense of self. Other participants also described experiences that are labelled as psychosis can be understood as having spiritual qualities that are connected to a person's wider experience. Given this conceptualization, it is important to explore and understand how spirituality is related to and a part of psychosis-like experiences.

Most participants drew on a range of experiences to describe how it is connected and functions as a part of the spirituality framework. Some focused on physical spiritual experiences, with Jerrod expounding on the importance of "healthy eating" (p.13, line 556) as not just a part of spirituality, but a potential mediator of psychosis, as it allows us to be "tempered in everything we do" (p.13, line 557). Similarly, Kareem cautioned against "wastefulness" (p.4, line 131) of "very precious" (p.4, line 132) natural resources, such as drinking water, when it can be used as a spiritual cleanse to “renew yourself and refresh yourself” (p.3; line 104 – 105) when experiencing distress. Other participants drew on the relationship between spirituality and subjective experiences; some used broad descriptions, such as experiencing “quietness and peace” (Jerrod; p.3, line 120-121) and feeling “hope…you’re comfortable” (Nadiyah; p.5, line 181). Wilma, however, drew a more direct relationship between psychosis, subjective experiences, and spirituality. First, she defined subjective spiritual experiences as “whatever makes your heart sing” (p.2, line 62), which can include a range of activities that make one feel “joy…connected…support” (Wilma; p.2, line 62-63). Second, she emphasized the importance of services seeking out an understanding of these subjective experiences, especially how a person is experiencing their psychosis:

> *“It depends on the service-user. Because some people might hear and see things that other people can’t and be totally freaked out by that…and then there are other people who will experience the same thing, and…actually quite enjoy it… they’ve got, I don’t know spirit guides or what they call spirit guides, or friends who are in spirit” (line 322 – 328)*

As argued by Wilma, it is important to understand how people’s subjective experiences of psychosis; some might find it frightening and others can feel an increased sense of connection to their spirituality.

The impact and influence of external factors on spirituality and psychosis-like experiences were also highlighted by participants, particularly nature. Here Kareem explains:

> *"…human being is not a physical body only but there is a spiritual being and the human spirit, human soul… God is unseen. You cannot see in this worldly life to his being. However, you can see the Signs of God the glorified in nature, in yourselves" (line 181-190)*

Kareem describes seeing not only the divinity in nature, but how it can be used to increase our sense of connection to experiences beyond the individual self. Wilma explained how this is related to people experiencing difficulties. She stated that because people with difficulties often "don't feel connected to anyone" (p.6; line 241 – 242), nature can serve as a non-judgmental relationship that accepts and validates them. She described it as such:

> *"We follow what the Earth does…so, that connection that I talk about will be going and sitting in the garden, um, or outside. Putting my bare feet on the ground, feeling the earth feeling, even if you even hug a tree. Sometimes you can feel the warmth of a tree, and you might get images in your mind, you know, or listen to the birdsong or feel the warm sun on your face and it's a form of connection to something that's not going to prejudge you, actually, and you know what, it's always there. And it can always nourish you" (line 230 – 248)*

Here, Wilma characterizes nature as a part of spirituality and spiritual experiences; as it is a part of the Earth, how we interact with it can provide support and connection we may not find elsewhere, particularly for those feeling alienated or isolated. The relationship between a person experiencing difficulties, like psychosis, and how they interact with their environment was seen as another example why a spirituality framework can allow for more exploration on psychosis-like presentations and how it relates to intertwining subjective, perceptive, and physical experiences. Psychosis's intertwining nature is also why Jason disagreed with notions that "divide" (p.9, line 356) psychosis from the mental, physical, and spiritual experiences, such as a biomedical framework, when "the truth is we are one entity, and those things are intertwined" (p.9, line 358).

Using the same framework, four out of six participants also likened science to a type of spiritual experience, seeing it is another way humans make sense of experiences like psychosis. When asked to explain how science belongs in this framework, participants drew on different ideas or understandings. Nadiyah simply characterized it as a "link in between" (p.4, line 169) that, while "explainable" (p.4, line 173), we have yet to discover how. Wilma on the other hand posited this link to be energy, and goes on to describe how it can be understood both scientifically and spiritually:

> *"Because I believe we've got an energy field within us, all of us. That's what keeps us alive. And when we die, the body just disintegrates and goes back to the earth again. But our spirit and our soul of who we are is energy. And I know from science [that] energy can't be destroyed. It only you know, evolves and, you know, and goes into something else and it just transforms, doesn't it, you know? So I do like to bring science like that in where I can, you know, especially with spiritual things, and I'll bring science in sort of. I think the most science I'll use is energy" (line 210-213).*

Here, Wilma uses the scientific conceptualization of energy to explain how it can be applied to spiritual experiences. She also demonstrates how it fits within the spirituality framework by using the idea of energy fields for the physical body and transcendent self. On the other hand, Mick suggested that the link between science and spirituality is in how they approach ideas:

> *"Because there are elements of both of those that actually rely on belief... um, it, Astrophysicists talk about dark matter. But they've never seen it [giggles]. So it's there are some things that we have to work on from a point of belief and we may not necessarily ever get to a point of proof that we feel comfortable with" (line 164-168)*

According to Mick, what makes science a part of the spirituality framework is that they both approach ideas starting from the position of belief, with some that may or may not be provable. In contrast, Kareem stated that while spirituality and science "both [go] hand in hand" (p.6, line 227), they are usually used for separate purposes within this framework, with science being used for experiences that can be explained "rationally with your intellect" (line 166 – 167) and spirituality does not. According to participants, acknowledging this link was important when working with psychosis-like experiences because of the possibility that a biologically-based illness may be occurring alongside other experiences. Science being a part of spirituality means that medical-based reasonings underlying psychosis would not negate other spiritual experiences happening as well.

All participants acknowledged that spiritual experiences occurring within this framework were not always helpful or beneficial. Spiritual experiences described by participants were characterized by both positive and negative examples. With the concept of energy, Wilma described it as enmeshed in our everyday experiences, which could increase our connection to spiritual experiences, but can also lead us to “energy vampires” that decrease our connection (p.5, line 178). She explained this meant being “totally drained of energy” (p.4 line 173) when trying to connect to our own or others spiritual experiences. This also applies to psychosis-like experiences, with Wilma expressing that when energy is spent on hearing voices or hearing “‘Spirit’ [it can] exhaust them” (p.5 line 196). This was similar to Jerrod’s conceptualization, except he focused more on how it affects the wider network. Because “‘Spirit’ are easily, um, transferred” (p.11, line 470) from person to person, Jerrod argued that carrying “generational curse[s]” (p.11 line 471) can occur as a result of past hereditary or ancestral actions; this can lead to negative spiritual experiences that affects families like spiritual possession or, in the case of “Hannah”, difficulties with her neighbors. Nadiyah, unlike Wilma and Jerrod, argued that negative spiritual experiences can happen “without any cause” (p.9 line 354) or control by the person, given that “it is natural [to experience] negativity” (p.3, line 130) in everyday life.

Due to the potential spiritual experiences being negative, Mick emphasized the need to “proceed with caution” (p.7, line 308 – 309) when exploring psychosis-like experiences within this framework, especially as some negative experiences may be attributed to “fixation[s]” (p.8, line 312) or “self-harm” (p.8, line 313). Likewise, Jason provided an example of a service-user who had certain spiritual interests that initially started off as helpful, but led to having a negative impact on him when he began to believe that he was a messenger of God:

> *“He was really into something called biblical numerology, which was…making sense of… the use of numbers…in the Bible, which is a whole particular area of theological*

> *study…his desire to try and interpret the future seen through numbers is a practice that's been practiced theologically for hundreds of years. But where it led him was to a place where one but virtually, 'I am the "Sent One"… these medical staff have got absolutely nothing to say to me, because they're all damned, and they're going to hell'" (line 222 – 240)*

We can see here Jason clarifying that biblical numerology is not inherently negative and is a legitimate topic of academic study. However, how it was utilized by the service-user in relation to their psychosis led to them disengaging from healthcare services, which otherwise could have helped support or navigate them through these experiences. This example also demonstrates that what makes these experiences positive or negative depends on how it is used and made sense of. Mick explained this duality by comparing it to foxgloves:

> *"…foxgloves. Nice flower to look at. But actually, if you take a very small amount of it, it can help with heart disease. But if you take more than a very small amount of it, it will kill you. And so you have in God's creation, both potential for Good and Evil dependent upon what we do with it" (line 689-692).*

Using the example of foxgloves, Mick compares the potential of our experiences – including psychosis – as being positive or negative depending on how we make sense of them, explore, and act upon them. This duality also highlights the importance of understanding the intertwining nature of psychosis-like experiences and how it can help to explore it multidimensionally, such as within a spirituality framework.

7.2. Theme II: Locating “psychosis” within a wider context beyond only the individual

According to participants, psychosis-like experiences being interconnected and intertwined means that, to make sense of it, its co-occurring physical, spiritual, psychological, and environmental aspects and experiences need to be explored. What *is* psychosis, however, was difficult for participants to explain and there was no universally agreed definition among them. Wilma, for example, defined psychosis both clinically and non-clinically:

> *“Okay, so obviously, you've got the clinical, uhh the clinical definition of that. So that's hallucinations, auditory and visual hallucinations, delusions of grandeur, etc….and then from my perspective, in my spiritual circles, people will often say that shamans experienced psychosis…because they are feeling, and they are connecting to a different dimension and a different realm” (line 72 – 79)*

This extract demonstrates two important qualities participants highlighted when defining psychosis: one, psychosis can have more than one definition, and two, psychosis can occur in a larger context. Wilma illustrates this by comparing psychosis-like experiences with shamanistic spiritual experiences. Nadiyah, on the other hand, described psychosis as possibly being a “lack of mental wellness” (p.5, line 211), but also as “evil whispers” (p.8, line 315) depending on how someone’s psychosis was being presented. Jerrod, Jason, and Kareem broadened their definition of psychosis, as an “experience that is irregular” (Jason; p.5, line 191) or “people who are affected” (Kareem; p.5, line 204). Jerrod explained this to be a deliberate choice to acknowledge and accommodate multicultural groups and the stigma associated with psychosis:

> *"It means for me, people who have challenges because I don't want you know, some of our Afro-Caribbean guys and, there's a lot of stigma, and they don't want to use the word…so, I don't push it in your face. I try to use terminology that they can identify with" (line 127 – 132)*

Here we see Jerrod adjust and tailor his definition to the intended audience, highlighting multiple ways psychosis can be understood. Mick also took this into account; he commented that the word itself means "generally just mental illness" (p.6, line 242), but alluded to how it is usually applied depending on when, where, and how psychosis-like experiences occurred:

> *"And she said to me, she said, 'If I go into church and I talk to God, people call me "Holy". If I go into church and God talks to me, Doctor so and so calls me "Paranoid Schizophrenic" again and puts me back into hospital'" (line 285 – 286)*

In this extract, Mick emphasizes the impact and effect of context by drawing a comparison between two environments, both in which the same behaviors are being exhibited, but only one receiving a "psychosis" label. Although Wilma acknowledged definitions of psychosis, she expressed not wanting to use terms that were "pigeon-holed" (p.2, line 57). Instead, she described using explanations that would help them "engage with their spirituality" (p.3, line 101):

> *"…so whether that is again a chemical imbalance… I try to say to them, 'Well, you know, you're here [in] this world right now and it's hard work having one foot in this world and one foot in the spiritual realm'" (line 304 – 306)*

Here we see Wilma describe how she would explain the spirituality framework to a service-user, highlighting its duality and overlapping nature, including a possible biologically-based illness. When it comes to defining psychosis, participants appear to allow for multiple explanations and possibilities, rather than one definition.

In general, participants considered psychosis harmful only if "it [became] disruptive for someone" (Wilma; p.7, line 288). However, participants differed on which experiences were considered harmful or not. With case vignette "Nadeen" Jason, Mick, and Wilma did not view her presentation as harmful. Jason came to that decision by considering the wider cultural and societal understandings of family, bereavement, and death when examining her case:

> *"…in Western society, the tendency is, is that sense of death is final or that person is dead. And that's it. But, but certainly certainly in African and also Afro-Caribbean kind of culture and, and and from what I understand in, in Asian culture, as well, you know, I would say that, that sense of connection to your ancestors is a really important aspects of of of life, and a little bit like, perhaps people in this country might go and visit a gravestone and speak to their mother or their father who's buried in the ground. Well, what what Nadeen here is doing is not any different from that. And my you know, my, my view would be as long as it it didn't become overbearing, or, you know, I think that, you know, you just, it's part of the grieving process... you know, these are themes that are you*

> *know, dealt with in films like "The Lion King". This is this is pretty mainstream in some way" (line 394 – 415)*

In this extract, Jason describes how he concluded that "Nadeen" was not a case of a harmful psychosis experience. By acknowledging how other cultures deem ancestral connections as important to maintain after death, he characterized "Nadeen's" case as a "mainstream" grieving process that intersects with other cultures, experiences, and conceptual understandings of life after death. Wilma came to the same conclusion, but emphasized the commonality of this kind of spiritual experience:

> *"So why shouldn't she speak with her dad whether he's in her head or a heart or whether his energy is next to her? You know, for me, I don't think there's anything detrimental there. It's not disturbing…[similar experiences like 'Nadeen' happen] all the time [giggles]. And they're not in hospital….Yeah, [it is] common" (line 508 – 519)*

As Wilma states, "Nadeen" believing she is speaking to her deceased father does not appear be causing a detriment or progressing any disturbances, normalizing this experience as happening "all the time" to people who do not seek or require hospital support. Mick made very similar arguments, but added that "Nadeen's" beliefs cannot be proven or disproven:

> *"…whether that is delusory [pauses] is almost irrelevant. It's not particularly causing anybody else any harm... And in many ways, if this is how she's coping with a [pauses] bereavement…It's not causing her problems in her functioning as a human being and so*

> *just because I don't understand it and how it's possible it comes to that thing of this isn't something that is necessarily going to lead me to think hang on there's a problem here that something [pauses] bad is happening" (line 554 – 563).*

Here, we see Mick consider several possibilities: a delusion, coping style, or genuine mediumship – all of which he cannot validate. Instead, what was important to Mick was the degree of harm these beliefs were causing to "Nadeen" and her wider network.

In stark contrast, Jerrod, Kareem, and Nadiyah viewed case vignette "Nadeen" as a harmful presentation that requires support. They emphasized less of the vignette's co-occurring factors and more on their faith-based positions. Based on his faith, Jerrod stated that "Nadeen's" was harmful and needed help because "Dead don't talk to people and cannot talk…you cannot talk to a deceased person" (p.10, line 401 – 403). Likewise, Nadiyah characterized "Nadeen" as one of "extreme connectivity…extremism…a very huge illness" (p.10, line 418 – 420), as it prevented the grief and "sadness [that] comes naturally" when someone dies (p.11, line 438). Kareem shared the same perspective, adding:

> *"…every being has to taste the death. That is a reality which no one can deny…so she is having some mental health issues" (line 432 – 434)*

Kareem states that, because everyone eventually dies, "Nadeen's" denial indicates mental health difficulties. Regardless of differences in perspectives, case vignette "Nadeen" helped highlight that not only did participants make sense of psychosis from the context of a service-user, but that it was influenced by their own beliefs and perceptions, as well.

Interestingly, participants were able to discern when experiences were related to mental health difficulties. With case vignettes "Hannah" and "Jimmy", five of the six participants characterized their experiences as "acute psychosis" (Wilma; p.10, line 412), "becoming mentally ill" (Mick; p.10, line 421) or "mental health issues" (Kareem; p.7, line 549). With "Hannah", Mick described her case as "mental illness rather than necessarily, um, from being tormented by evil spirits" (p.11, line 438). When asked how he came to that conclusion given psychosis's intertwining nature, he explained:

> *"A lot of it is about listening and about what happens in the beginning. And what happened just before the beginning" (line 439 – 447)*

In this extract, we see Mick's emphasis on listening to a service-user's perspective, their chronology, and sequences of these experiences when considering if causes are mental health-related. Wilma also shared the same view about "Hannah", and shared questions she would ask to help "locate" and contextualize the psychosis:

> *"…she talks about evil spirits and being cursed. So where has she got that information from? You know, has she been read- because I've had people say to me before they've been cursed since they've been using tarot cards and I've talked to them about that. So wonder where this has come from? Because has she been watching a TV program? Has she read a book? What does she think about that? You know, is it from a Christian upbringing? Has she been talking to people from spiritual circles…it could be that*

> *somebody wants to speak with her, or, you know, and does that worry her? …but then…[it] could definitely be an imbalance in the brain" (line 412 – 425)*

Here, we see Wilma consider several potential sources of "Hannah's" beliefs around spirits and curses, including biologically-based reasons. Nadiyah described working within the spirituality framework when considering if "Hannah's" case was mental health-related, in particular diet and sleep, because "if they're not eating properly…[this can] make them hear voices" (p.8, line 313 – 314). Not all participants, however, used or agreed with this process of discernment. Jason argued that discernment would not be possible or helpful for "Hannah":

> *"…those two things are so intertwined….the idea that you can extract one from the other is, is you know, you're in danger of actually doing more damage and so and so the person needs help from a mental health perspective, but the person also needs help from a spirituality perspective" (line 354 – 361)*

Here we see Jason reiterate the spirituality framework and its intertwining nature with "Hannah". According to him, discernment may be a danger, potentially reducing support for her to one perspective rather than using a combined mental health and spiritual approach. Interestingly, with case vignette "Jimmy", Jason described it as "schizophrenia" (p.11 line 476) that would require medical and mental health support first. When asked why, he described the presentations in this vignette as "much deeper" (p.11 line 475) and progressive in disturbance than the other vignettes. All other participants agreed "Jimmy's case was mental health-related given the harm that occurred and that he required medical support. Jerrod was the only participant to emphasize a potential co-occurring spiritual experience; he considered the possibility that “Jimmy” was “possessed” (p.11 line 460) but emphasized mental health and medical support first. “Jimmy’s” spiritual abuse was highlighted by all participants as an important reminder of how spirituality can be exploited and become a harmful experience.

7.3. Theme III: Chaplaincy as a holistic and bespoke approach to recovery from psychosis

When working with psychosis, participants described their approach in spiritual services as holistic, validating, empowering, and tailored to the service-user's goals and needs. Kareem expressed it as such:

> *"Chaplaincy department can provide help [in] other therapy, you know, provide health [in] all that contribute to the wellbeing. It's the whole package... 'Cause sometime, social aspects are crucial, you know, sometime their matrimonial problems making them, you know, possessed. It all depends" (288- 290)*

Here we see Kareem emphasize the "whole package" of a person and the various difficulties that can be addressed. All six participants emphasized holisticism in psychosis recovery. Jerrod expounded:

> *"...you have to be there for them in a fair [way] and try to keep it balance and just support them on making sure that they, you know, they have access to resources that they need to help them on their journey. And just making sure that they are getting a holistic care package, so to speak" (line 73-77)*

In this extract, Jerrod describes holistic working as including support and resources based on the service-user's needs, characterizing it as a fair and balanced approach. These resources could also be religious; five out of six participants indicated using prayer and religious objects or totems, such as amulets, prayer cards, water, and holy books to help bring a service-user "peace"

(Mick; p.12, line 484) and “heal” (Nadiyah; p.3, line 95). Non-religious resources on the other hand were described more generally, such as being a “listening ear” (Jason; p.1, line 25), but also:

> *“Some people they just need company…some people they like to discuss their family problems. Some people, they have some social issues, and some even they have some you know, social services issues” (Kareem; line 252-255)*

Here, Kareem provides different examples of non-religious support depending on the service-user’s needs from chaplaincy. According to Jason and Jerrod, the variety of resources also allows them to provide tailored support for people experiencing psychosis that come from diverse backgrounds, paying particular attention to individual and cultural differences:

> *“Different strokes for different folks, everybody will be, um, be different. And bring in their culture. Try to identify with some of their culture and what they're used to. Especially with some of those who are very culture-orientated. And try to adapt to some of the culture from, you know, from Africa, from India, from the West Indies, and try to reflect and adapt some of that” (Jerrod; line 203 – 206)*

In this extract, Jerrod describes how, under the umbrella of “different strokes for different folks”, he utilizes resources that are appropriate to a service-user’s identity and culture and uses reflective skills to help tailor support.

Validation and acceptance were also part of holistic care for people experiencing psychosis, according to all participants. This included “supporting them whatever stage they’re at” (Wilma; p.14, line 611), “[letting] them be themselves” (Jerrod; p. 5 line 199), “believing them” (Wilma; p.9 line 387) and “[listening to] them” (Nadiyah; p.1 line 25). Mick explained this as different from enabling and agreeing with service-users’ views, clarifying:

> *“There are times when people told me of experiences and I would say I believe them in terms of their undoubted sincerity. I do not understand how I have to accept that in effect in faith. And that has to be because we can't know everything….But just because I don't know doesn't mean it cannot be” (line 192 – 199)*

Here, Mick makes a clear distinction – he can validate service-user’s beliefs about what they are perceiving without accepting it to be objectively true. The extract also shows that, even if Mick cannot verify a service-user’s beliefs, he would be not consider it a barrier to his chaplaincy work with them. Jason expressed a similar perspective:

> *“People can have views that are warped, but you can't just dismiss those views. You've got to work with them. And you've got to help that person to make sense of them and, and also help to level with them so that they can come to a more considered understanding of the stuff that they're reading, taking in or believing” (line 241 – 244)*

In this extract, Jason emphasizes the importance of hearing views even if “warped” in order to support the person in their recovery. Validation and acceptance were most apparent with case vignettes “Hannah” and “Jimmy”. With “Hannah”, Jerrod characterized it as such:

> *“You're accepting what she's saying…We are not shunning it, we are not pushing it away. We are accepting. Because sometimes they can be very adamant and argumentative. And we say ‘We know you are feeling suicidal. We know that sometimes, um, you you you your neighbor has cursed you. So we believe what you're saying, Hannah” (Jerrod; line 369-372)*

In anticipation of “Hannah” becoming argumentative, Jerrod would accept what she is saying without “shunning” it, acknowledging her suicidal thoughts and beliefs about being cursed. With “Jimmy” Mick validated his experiences by highlighting the impact of religious abuse on “Jimmy” rather than encourage a return to faith:

> *“…it's religious abuse and there's therefore going to be a lot that actually is going to need unpacking with this that a part of what's happened for Jimmy. And that whether he comes back to a belief in any higher power is in, um, some ways, not irrelevant, but is is not necessarily something you can unhook. And that's because of the abuse he has suffered. And the fact that this was mainly financial rather anything else doesn't make any real difference. It's still the fact that he has been abused. His trust has been abused. He has been manipulated by people and that has been done in the name of religion” (line 658 – 664)*

Along with acknowledging religious abuse, Mick states here that the purpose of working with “Jimmy” would be to unpack his experiences rather than reinstate his spiritual beliefs, which may no longer be possible – a perspective that was shared by all participants. However, Jerrod also added that having a conversation with “Jimmy” about his options to engage with his spirituality or chaplaincy can be helpful:

> *“I would say to Jimmy… ‘I'm not gonna try to indoctrinate in any shape or form. Whatever this is gonna take, I'm happy to support you. But if anytime in your journey you do think, you know, you want to know more about God, you know, I am still here to support you. And I will be still praying for you.’ So, you know, I still give him, I still leave the option for for for Jimmy to visit and to get spiritual care if he do need help. So I don't shut it down. I don't shut him down. I say, ‘Eh, I'm still here to support you. I'm still here with you on your journey. You really want to continue what you're doing and I will continue doing what I'm doing but whenever you're ready’” (line 519 – 525)*

In this example, we see Jerrod providing validation, acceptance, and tailored support. Emphasizing it is an “option” to work with chaplaincy, Jerrod reiterates that support from chaplaincy is available to those who want it as part of their recovery.

There appears to be exceptions on what beliefs or perceptions can or cannot be accepted or validated. Since views were split on whether “Nadeen” was having a harmful experience or not, participants also differed on what chaplaincy approach to use. The participants that characterized her beliefs as not harmful described an acceptance-based approach: “[giving] her space" (Jason; p.10, line 427), offering support only if "Nadeen wanted [their] help and support" (Wilma; p.13, line 526), and being available to support "Nadeen's" significant others. Participants that characterized "Nadeen" as having a harmful experience chose approaches based on their faiths. Kareem, for instance, said that with "Nadeen" he would be "sympathetic [and] not judgmental" (p.11 line 454) but will "need to explain to her [religious] teachings about death" (Kareem; p. 11 line 454 – 455). Jerrod also described using the same faith-led approach:

> *"So you have to come up with thoughts to prove to her that what's happening to her is not real. Maybe take her out into the cemetery and say 'Look this is where your dad is'... So I I I I I just tend to not go around the bush, I just come simple and direct. I just straight the point, yeah? I'm just gonna go straight the point and say, 'No you cannot talk to a deceased person'" (line 397 – 403)*

In contrast to case vignettes "Hannah" and "Jimmy", Jerrod described a more straightforward dialogue with "Nadeen," emphasizing these experiences as objectively not real and would consider showing her where her dad is buried to help accept her father's death. Nadiyah had a slightly different faith-led approach; she described giving "Nadeen" three options, "healing treatment from religion or via treatment from the medications...or [from both]" (line 458 – 459). Although approaches differed, participants were still able to demonstrate how they would work within the spirituality framework to make sense of these experiences holistically.

Empowering service-users to be actively involved in their own care was also characterized by all participants as part of spiritual care for psychosis. Mick noted:

> *"…I can't come in necessarily wave a magic wand and bless you, and everything is going to be okay…it's got to be about what are you going to be able to do to bring yourself to peace with that…This is not a 'Get Out of Jail Free' card" (line 514 – 521)*

Here, Mick states that chaplaincy support is not a "magic wand" but instead encourages self-management, responsibility, and empowerment rather than paternalism. Empowerment could also include being "upfront" (Jerrod; p.10 line 409), like Jerrod's approach with "Nadeen", as well as through affirmations with service-users that "they're stronger than they think" (Wilma, p.9 line 388) and "giving [them] alternative[s]" (Kareem, p.11, line 476) about the types of resources they can request from chaplaincy. With "Hannah", Jerrod gave a clear example of how he would empower her:

> *"I would get a blank sheet of paper and I would, write, uh, draw a line and I would write all the negative things that is happening to the individual. And then I would write all the positive things that is happening to the individual. Sometimes the positive outdo the negative, sometimes the negative outdo the positive. When the positive outdo the negative, I say, 'Well you have more positive than negative', Yeah? But I wanted her to take away one positive from this and t-try to work upon it" (line 312 – 317)*

Similar to an acceptance-based approach, Jerrod described not only validating "Hannah's" views, but focusing on facilitating self-improvement skills. Whether these tools are applied by the service-user or not, participants emphasized supporting them in "[making] their own decision[s]" (Jerrod; p.5 line 207), as chaplaincy is not necessarily about "…[guiding]

people. But certainly… to give a religious perspective and then leave people to make their decisions" (Jason; p.3, line 110 – 111). This also reiterates the perspective that chaplaincy is supportive, validating, and empowering, but not a "magic wand" (Mick, p.12, line 514).

As participants deemed science as part of a spirituality framework, all participants noted that holistic work with psychosis often includes medical support. As "God has given us [gifts] in terms of creation [which] includes pharmaceuticals" (Mick; p.16 line 682 – 683), all participants supported an integrated approach, where "prayer and medication [work]" (Jerrod; p.3 line 109) in combination. However, this was seen as a challenge to implement in services, with participants characterizing mental health services as favoring more medical frameworks for psychosis recovery than a holistic one. Mick in particular stated:

> *"…we're both here to help by coming from a different place, we're not here to contradict each other, but equally, we're not the other person, and we need to keep some of that balance" (p.13, line 530-541)*

Here, Mick states that both a medical and spiritual approach can complement rather than contradict the other, as long as the roles are made clear. Some participants like Jason noticed services have improved in their "acknowledgement of spirituality" (p.2, line 54 – 55) and spiritual care, however, there is still "room for improvement" (Jerrod; p.4 line 174). In the following extract, Wilma describes her experiences of working holistically with psychosis alongside medical doctors:

"Well, I think sometimes, just like everywhere, there are some doctors that are better than others, shall we say, and you will get some that are, 'No, no, no. It's definitely a chemical imbalance', won't look at anything else. That's it. Medication, medication, medication, and then you'll get some that are more open minded shall I say, you know, and I have, I've worked with both kinds of doctors really, you know, and the doctors that are more open minded, tend to be more, um, sympathetic and listen" (line 296 – 301)

Here, Wilma compares two medical approaches: one that uses a framework that is mostly based around medication, and the other that includes more of the service-user's perspective in their care. She described a preference for the latter approach, as it is easier to use her holistic approach alongside.

Kareem also emphasized that, aside from how integrated approaches can help service-users, it can benefit healthcare providers, too. He recalled that, when he worked in mental health services that were facing difficulty and confusion with service-users' "cultural barriers…particularly [in practicing religion] seriously" (p. 6, line 228), chaplaincy contributed and "made a full picture… [which was] very helpful" (line 228 - 230) for both the service-users and healthcare providers. Jason shared similar examples, adding that healthcare providers often find it difficult to navigate spirituality-related topics with service-users, but that spiritual care can and has helped:

"…working with other clinicians to ensure that the spiritual care of the services users part of their overall care plan…sometimes I will be invited into sorts of clinical supervision meetings with service-users to to input because I had been sort of one of the health professionals kind of inputting into the, the, the, the well being of that patient or of

> *that service-user. I will be asked my advice on a variety of different things that perhaps come up kind of in clinical supervision. So for example, it might be a psychiatrist or a psychologist has a conversation about spirituality, and, erm, and then relays that conversation back to me a conversation that they've had with a service-user and just wanting my advice" (line 33 – 38)*

Here, we see the role that chaplaincy can play in supporting other services to make sense of spirituality and the role of this in their own work. It also shows how a holistic approach can be helpful beyond the boundaries of spiritual care services.

8. Discussion

The aim of this study was to explore how spiritual care staff make sense of their work with service-users having psychosis-like experiences.

8.1. Summary of findings

All participants acknowledged the term “psychosis” as a label that is applied to certain experiences. These experiences were characterized as a part of spirituality, as they relate to or affect a person’s overall awareness, wellbeing, or quality of life in both positive and negative ways. Therefore, psychosis is not an independent event, but co-occurs and overlaps with environmental, psychological, biological, and spiritual factors. What exactly *is* psychosis was not universally defined, which appeared to be a deliberate choice made by participants who often work with a diverse range of service- users, altering the definition to suit different cultural, ethnic, or spiritual understandings of how psychosis.

Some psychosis-like experiences could be seen as harmful or more related to mental health issues than others, depending on the participants’ faiths and the degree to which these experiences have caused a disturbance to the service-user. Some participants would rely on religious resources to explain why some experiences, such as the belief one can speak to the deceased, are harmful to the person’s wellbeing while others took the position that these beliefs can neither be proven nor disproven, and would utilize non-religious resources, such as acceptance and validation, which can be considered psychotherapeutic as well. For all participants, being non-judgmental and preventing “indoctrinating” service-users was important, as well as accepting that service-users who have had negative experiences with spirituality and religion, might want chaplaincy to only play a limited role in their care.

All participants described a holistic approach when working with psychosis. Science and medical involvement were one approach to care, which participants complemented with religious resources (if requested by service-users) and non-religious resources. Validation, acceptance, and empowerment was a priority, as well as asking service-users about their needs and how best to support these. Using this approach within mental health services was reported to have had a mixed reception; some participants described staff allowing both psychiatric and spiritual care to work side-by-side while other staff emphasized medical-based recovery for psychosis. Participants reported that there has been improvement in services in acknowledging spirituality, but there is room for improvement, including more opportunities for spiritual care to consult staff on service-users' cultural or religious beliefs about psychosis or supervising them in becoming more comfortable exploring spiritual topics with service-users.

8.2. Clinical and research implications

8.2.1. *Psychosis*

Psychosis not being defined appeared to be neither barrier nor priority for participants. While this could be because defining psychosis in services is usually delegated to diagnosticians, it could also be because their holisticism does not necessitate a definition for psychosis in order to work with it. Interestingly, there appears to be a contrast in priorities on this topic: how psychosis and spirituality is researched is very different from what participants deem as important. We currently have a range of literature

on theoretical underpinnings discerning psychosis from spiritual experiences (Fulford & Jackson, 1997; Greyson, 2014; Hunt, 2007; Randal et al., 2018), which differs from participants' emphasis on holistic working and accommodating service-users' perspectives and needs, regardless of whether these experiences can or should be discerned. This indicates that more research is needed in the knowledge base on spiritual care perspectives and work with psychosis *in practice*, as opposed to theory-dominant literature.

Participants viewed psychosis as being entangled with the person themselves and that its intertwining nature makes the service-user's perception of these experiences important to understand and work with. This perspective also appears in narrative literature where it highlights the challenge of biomedical perspectives on psychosis and how it can lead to a "circular assumption" by medical staff, declaring service-users to be lacking insight if they choose make sense of psychosis differently (Mariott et al., 2018). "Wilma" described similar challenges when working holistically in mental health services, as either being accepting of service-users' perspectives that are not biomedical or rejecting it. Narrative literature also appears to argue for a "multidimensional" framework when working with psychosis, which is very similar to participants' holistic working, but with more emphasis on insight (Pijnenborg et al., 2013). With this in mind, it should be noted that most clinical-based and research-based literature continues to remain diagnostics-based, and it is hoped that the current debate on the appropriateness of diagnoses will allow more opportunities for alternative, yet integrative approaches toward psychosis.

The perspective that psychosis is a part of a spirituality framework has also been previously considered in research. In a 2019 Foucauldian discourse analysis on mixed case reports by Kaselionyte and Gumley, they identified non-medical framings and non-pathologizing of mental health difficulties as having potential for "spiritual growth and healing." What that meant exactly and what resources were needed were up to the service-user, which participants also emphasized in our findings. The spirituality framework, which has psycho-spiritual concepts, are also echoed in integrated models like Positive Psychology. Positive Psychology models appear to be very similar to spiritual holistic care and spiritual interventions, which has not gone unnoticed by researchers interested in the science of personal strengths and happiness (Carr, 2011). In fact, they have been described as going “hand in hand” (Barton & Miller, 2015) since they both emphasize gratitude, transcendence, hope, and character strengths such as resilience (Browne et al., 2018).

However as Positive Psychology emphasizes empiricism (Wong, 2011), very little of their research, if at all, utilizes spiritual care perspectives on these topics. For example, Positive Psychotherapy (PPT) has been shown to be helpful as a manualized intervention for psychosis (Riches et al., 2016), however these are still not being conducted alongside or consulted with members of spiritual care services. Therefore, future research could focus on the applicability and efficacy of integrated psycho-spiritual models, such as the “extended biopsychosocial model” (Hefti, 2011). This could help promote integrated models in services, make it more convenient to combine multidimensional psycho-spiritual concepts as part of service-users’ recovery from psychosis, and begin to close the “religiosity gap” that has been highlighted in previous psychosis research (Van Nieuw Amerongen-Meeuse et al., 2018). Further, including spiritual care perspectives when examining the efficacy of integrated models could lead to a much-needed redefinition of “religiosity” in research, as it is currently measured according to Judeo-Christian concepts of White, North American populations (King et al., 2013).

8.2.2. *Spiritual care within mental health services*

Participants described the spiritual care approach towards psychosis as being holistic, validating, and empowering. Similar to psychosis and spiritual care, research on chaplaincy in mental health care has mostly been delegated to theoretical writings than practice-based research

(Pesut et al., 2010). Practice-based research was mostly found in either nursing or palliative care. It is unclear as to exactly why there is less breadth on this topic, but it can explain participants' observations and experiences of healthcare providers not feeling confident when working with spiritual-related topics, especially those not working in or researching nursing or palliative care. This not only contributes to the "religiosity gap" but highlights participants' reports of mixed reactions from staff on spiritual care. Further, current attempts to close this gap by including spiritual care in Multidisciplinary Teams (MDTS) are still an adjustment, with some questioning the ethicality of what is or is not considered confidential to members of MDT that are not healthcare providers (Jankowski et al., 2011; Wittenberg-Lyles et al. 2008). With that said, studies on service-users and family perspectives show that when spiritual care has been utilized in MDTs, their input and rapport was valued for reasons participants also listed in this study: validation, acceptance, and empowerment (Balboni et al., 2010; Heffernan et al., 2016; Ho et al., 2017; Raffay et al., 2016). Further, a 2010 systematic review by Edwards and colleagues on spiritual care in end-of-life and palliative care demonstrated that service-users found spiritual support to improve their quality of life, increased family satisfaction with services, and service-users reported feeling they were "respected as a whole persons." This highlights holisticism as a central theme in spiritual care, not only when working with psychosis, but of any mental health difficulty presenting in services.

Given there are several studies demonstrating that people from diverse backgrounds use spiritual explanations to make sense of their psychosis (Codjoe et al., 2013; Huguelet et al., 2010; Singh et al., 2015; Zafar et al., 2013), this can make it challenging for healthcare providers because most clinical research conceptualizes spiritual beliefs and religiousness as coping styles rather than a method of care they can work with (Marriott et al., 2018; Mohr et al., 2012).

Therefore, more routine service outcome measures are needed that explore spiritual needs beyond coping styles. Further, as “Jason” and “Kareem” suggested, it may also be beneficial to promote more communication between spiritual care and mental health care, such as through consultation or supervision. In fact, there has been some evidence suggesting that spiritual consultancy may be protective against burnout for staff, preventing emotional exhaustion (Ho et al., 2017; Sinclair et al., 2012). Despite little research in the current knowledge base, it does seem important to continue to improve integration of spiritual care in mental health, and one way to do that could be by having a better understanding of chaplains, their training, and resources they can offer to support service-users.

8.2.3. Implications for mental health services

Modifying psychosis diagnoses is becoming an increasingly important research priority, with some advocating for stricter diagnostic criteria to reduce errors in cross-cultural psychiatric assessment (Adeponle et al., 2012). However, after reviewing the DSM-V, Paralikar and colleagues (2019) instead have argued for more nuanced approaches and supplementary support to make sense of a psychosis-like presentation. While they emphasized the importance of spiritual exploration by clinicians as part of their clinical formulation interviews, they did not explicitly acknowledge or state spiritual care as potentially integral to this. This highlights another challenge in current research: most studies on spirituality and spiritual care are conducted by researchers with a medical or psychological background (Basset & Baker, 2015; Dein, 2017; Lucas, 2017; Saavedra, 2014; Suhail & Ghauri, 2010; Van Holten 2012; Waltman, 2013), which could explain why it is uncommon to see other perspectives or backgrounds included in research. It could be helpful for future research to include perspectives from spiritual care alongside medical, psychiatric, or psychological backgrounds.

Mental health services may also benefit from interview structures that help clinicians determine spiritual needs. This might be especially helpful when working with service-users from minority backgrounds and their family members and/or carers (Penny et al., 2009). Currently, we have a range of spiritual assessments that aim to integrate both clinical skills and spiritual explorations (Milner et al., 2019)[4], which can be either structured or semi-structured. While a structured interview can yield more confidence for healthcare providers to ask questions about spirituality, a semi-structured interview may allow for greater rapport-building and trust that participants in this study described as important. Either way these assessments, along with consulting with spiritual care more often, might help close the "religiosity gap" and yield better outcomes for service-users, healthcare providers, and services (Ho et al., 2017).

What also appears fundamental to spiritual and mental health care integration is making spiritual care more visible in daily care (Giske & Cone, 2012; Islam et al., 2015). Suggestions from service-users have included spiritual care education and training (Yardley et al., 2009). Indeed, there has been some evidence demonstrating service improvements as a result of spiritual training: better integration of clinical and spiritual care skills (Trevino, 2014), more reported confidence from healthcare providers on spiritual-related assessments and topics (Jackson et al., 2016; Kudubes et al., 2019; Selman et al., 2014), and mental health-related textbooks being updated to include guidance on spiritual-related matters (McSherry & Jamesion, 2011). Further, a 2015 systematic review by Paal and colleagues found spiritual care training led to more acknowledgement of spirituality by clinicians, as well as positive communication with patients and family. Future research could explore the impact of spiritual care integration within mental health services from the perspective of clinicians, spiritual care staff, and service-users.

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[4] Clinical-spiritual assessment tools include FICA, SPIRITual History, FAITH, and HOPE (Weber & Pargament, 2014)

8.3. Evaluation

This study was evaluated through guidance by the Critical Skills Appraisal Programme (CASP) Checklist for qualitative studies and the four "quality indicators" for appraising an IPA from Nizza and colleagues (2021).

8.3.1. Limitations

A limitation to this study could be that it is not generalizable in the way a quantitative study would be. However, qualitative studies do not aim for generalizability but rather on exploring very particular perspectives on a particular topic. Further, given the little research on spiritual care staff in both qualitative and quantitative research, generalizability may not be desirable until both breadth and depth on this topic has been achieved. Another limitation is that while the participants matched the inclusion criteria, it was a multi-faith sample with diverse backgrounds and beliefs and some views greatly contrasted. Therefore, one could argue that a single-faith sample may have yielded greater homogeny; however, the researcher did consider multiple levels of experiential significance and consulted her research supervisor over the findings throughout the analytic process to ensure that themes were relevant to the whole group. It should also be noted that the research was wholly conducted by one person (the Trainee), which enhances the risk of researcher biases throughout the study including interview and analysis. A reflective diary was used to enhance the researcher's awareness of her biases, however due to the nature of qualitative methodologies, biases are impossible to eradicate from a researcher's analysis. With this in mind, the analysis was regularly reviewed in a qualitative support group for transparency and trustworthiness.

8.3.2. *Strengths*

This study had a clear statement of the aims of the research in question and why the use of a qualitative methodology would be most appropriate, namely, to explore meaning-making experiences. The study topic itself could also be seen as a strength, as it appears to be a topic that is underexplored in certain areas and from certain perspectives, but also over-explored in other areas that take a more theoretical, but not practice-based view. Using both case vignettes and a semi-structured questionnaire as part of the research design helped facilitate nuanced discussions and reflections from participants. This allowed the researcher to conduct data collection in a way that helped yield richer data by exploring meaning-making experiences in more depth than either an interview-only or vignette-only data collection method could allow. The recruitment strategy followed a clear protocol approved by the relevant governance bodies, which led to participants that matched the inclusion criteria. Data analysis and findings were also aimed to be explained in a way that was easy to follow, accessible, and transparent. A reflective diary was kept to help pay close attention to biases, attitudes, or beliefs the researcher had throughout the process, which was reviewed and discussed with her supervisor throughout.

8.3.3. Reflections

Given my interest in spirituality, psychosis, and in holding my own spiritual views, my reflective diary was used after every interview. I explored my attitudes and beliefs towards the different faiths held by participants, which was utilized appropriately in my analysis. For example, I bracketed my own faith-held beliefs of life after death in order to engage in different conceptual understandings of death, life, and mediumship because I wanted to ensure participants' perspectives were highlighted and explored in-depth. I also bracketed my understanding of psychosis based on what I have been taught at academic institutions and services in order to immerse myself in the participants’ worldview of psychosis as part of a spiritual framework. This led to reflecting on the differences between theoretical versus practice-based understandings of psychosis and different ways it can be understood. I also reflected over certain terms that were used by participants like *empowerment* and *not a magic wand*. I found those concepts powerful but was aware that not all participants described them as such. Noticing this as a potential danger to the analysis, I aimed to ensure that there was a balance in that all participants were given an equal “voice” to the analysis regardless of concepts I may have resonated with more than others.

8.4. Conclusions

The aim of this study was a qualitative exploration (IPA) of how spiritual care staff work with service-users having psychosis-like experiences. Participants characterized psychosis as one of many spiritual experiences that are intertwined with the person’s biology, psychology, environment, and spirituality. Integrating spiritual care within the work of existing mental health services requires ongoing conceptual and practical considerations that were recognized and discussed by participants.

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CHAPTER III: PUBLIC DISSEMINATION

EXPLORING PERSONAL ACCOUNTS OF THE FACILITAORS AND BARRIERS TO SEEKING HELP FOR FIRST EPISODE PSYCHOSIS (FEP): A META-ETHNOGRAPHY

&

SPIRITUAL UNDERSTANDINGS OF PSYCHOSIS: THE PERSPECTIVES OF SPIRITUAL CARE STAFF

Literature review: Personal accounts of the facilitators and barriers to seeking help for First-Episode Psychosis (FEP): a Meta-ethnography

Background

We do not know what causes psychosis, but we do have some idea of what it looks like when a person first begins to experience it, otherwise known as “First Episode Psychosis (FEP)”: hearing voices, seeing things that others cannot, or having “odd” beliefs. It typically becomes a problem when the person finds it difficult to tell apart FEP experiences and their “reality.” This can lead them down a dangerous path where they may hurt themselves or others. For this reason, mental health services have prioritized helping people with FEP as soon as possible. Reham Al Taher, a Clinical Psychologist in Training at the University of Birmingham, wanted to focus on giving a voice to the people that have lived through FEP and their road to seeking help.

Method

When researching this topic, Reham found two important things: one, several researchers have already interviewed people that have experienced FEP and how they sought help (or not), and two, there were a total of 15 research studies from her much larger searches that, when combined, could explain what is happening on a larger scale. In combining, reviewing, and analyzing the studies she used a research technique called a “Meta-ethnography” that helped her better understand these experiences.

Findings

The results suggests that at the early stages of FEP, changes are subtle enough where most do not seek help because of how easy it is to say these changes are happening because of something else like stress or not getting enough sleep. As FEP intensified, feelings of doubt grew about what exactly was causing these changes. Most still did not seek help at this stage. What we usually saw next were more elaborate explanations of what is causing these changes.

Some explanations included being victims of a conspiracy by the government. Others believed changes happening were due to a religious curse or demons. This either led them to seek help out of fear or delayed them from seeking help. For example, if they believed they were victims of a conspiracy some sought help from the police, which eventually led to mental health services. If they believed this was due to religious reasons, they may have sought out a religious group instead. At this point their loved ones and services would notice these changes and become more involved. Whether or not this was helpful depended on if the person had a good relationship with them already. If they did, this led to them disclosing their experiences. With positive support, help was sought faster and more effectively. If there was mistrust, negative experiences and relationships, and a fear that society and loved ones will ostracize them, then help may have been delayed or dismissed. Throughout this, seeking help was also influenced by their culture, family norms, gender stereotypes, and ethnicity.

If help was not sought or was effective at this point, most entered a crisis and emergency help was often the go-to since they were now becoming high-risk: becoming suicidal, experiencing homelessness, losing employment and so on. When recovering from FEP, it seems that some services asked them to accept that this all happened due to purely medical or biological reasons. Not all were satisfied with that. Some wanted a "recovery style" that blended their own interpretations too, as this entire experience was deeply personal and was affected by and influenced their beliefs, relationships, cultures, and ethnicity.

Conclusions and recommendations

Seeking help for FEP appeared to be influenced by relational, cultural, individual, and systemic roles. Based on the results, the following recommendations were offered:

- Provide mental health support that allows room to explore personal accounts of FEP, especially how they bring in their identity, families, and culture to make sense of their experiences.
- Acknowledge and work on building effective, supportive, and positive relationships with service-users and their significant others.
- More research focus on effective organizational and cultural changes that can help better the relationships between service-providers and service-users.
- More research focus on helpful “recovery styles” that service-users can use make sense of psychosis in a way that is most helpful to them and the service, versus a medical-only based understanding of psychosis.

Empirical Paper: Spiritual understandings of psychosis: the perspectives of spiritual care staff

Background

When a person enters a mental health service and reports they are hearing voices, seeing things that others cannot, and having “odd” beliefs, some healthcare providers may diagnose it as “psychosis”. Sometimes this person also holds spiritual or religious beliefs and some of their “odd” beliefs, voices, or visions mirror their spirituality or religion. To illustrate, say a person is reporting that a deceased loved one has been visiting and speaking to them and as a result their mood has improved. This can make it difficult for mental health services to know if this is “psychosis” or a spiritual or religious experience. In mental health services in the United Kingdom (UK), we have been seeing spiritual care services working alongside healthcare providers to help support people having these experiences.

There is very little research on spiritual care services and how they understand and work with experiences otherwise termed as “psychosis”. Reham Al Taher, a Clinical Psychologist in Training at the University of Birmingham, sought to explore how spiritual care staff understand and work with service-users experiencing “psychosis”.

Method

Reham interviewed six participants from a spiritual care team in a mental health service in the UK. The interview consisted of questions about psychosis, spirituality, religion, mental health services, and spiritual care, as well as three case vignettes. These vignettes had different scenarios featuring issues that had both psychological and spiritual elements. For example, one vignette was a woman who believes her deceased father has been visiting her and her mental health as a result has improved.

However, her husband is worried if this is a sign of mental health issue. Because Reham was interested in understanding experiences and how people find meaning in them, her research was analyzed using a tool that is referred to as an “Interpretive Phenomenological Analysis (IPA). This tool allowed her to explore the *meanings* of these experiences in depth.

Findings

The results of her analysis found that all participants acknowledged the term “psychosis” as a spiritual experience because of how it affects a person’s wellbeing, their connection to others, their identity, their environment, and their mental health. This can be both positive and negative depending on the person’s circumstances, but most part participants saw these experiences as being more than *only* a disease or mental illness. What *is* psychosis was not defined and was not considered important to define because they worked with the whole person, rather than just their mental health or spiritual beliefs. Their work consisted of asking people how to best support them and meet them at whatever stage the person was at. This could be prayer, but also being non-judgmental, accepting, validating, and empowering.

However, not all spiritual beliefs were considered helpful and as participants were of different faiths, some of their perspectives differed on what was considered a “harmful” spiritual belief or experience. However, all supported using psychiatric medication for psychosis, but said that services could be overly-reliant on medication and that providing support for psychosis could benefit from a more inclusive approach of what the service-user wants, their spirituality, and by considering perspectives of spiritual care staff that have been working with the service-users as well. Participants have stated that while services have acknowledged spirituality in mental health services, there is more room for spiritual care to be involved in consultation and supervision.

Conclusions and recommendations

Psychosis can be seen as a spiritual experience that intertwines with a person's physicality, psychology, and environment. Using spiritual care, which works holistically with psychosis, can be helpful for the service-user, healthcare providers, and services. Based on her findings, Reham recommends:

- More research on alternative ways of making sense of and working with psychosis-like experiences.
- Future research exploring integrative "psycho-spiritual" models for mental health services.
- Future research on psychosis to include perspectives from spiritual care staff rather than only medical, psychiatry, or psychology.
- More focus on increasing healthcare providers' confidence when working with a problem that has elements of spirituality and mental health. This could be via spiritual care training, education, and updating mental health-related manuals with guidance on spirituality and spiritual beliefs.

Appendices

Appendix A. Full table of study characteristics

Author, year of publication	Country	Publication	Epistemological position	Aim (s) of study	Intervention	Analytic tool	Data collection and analysis
Amanda Spikol and Jamie Murphy; 2019;	Northern Ireland	Clinical Schizophrenia & Related Psychoses	Not stated	Examine lived experiences of early psychosis, including help-seeking	Reddit post non-researcher posted " People that have been diagnosed with schizophrenia, what was the first time you noticed something wasn' t quite right?" and researchers used IPA to analyze secondary data	IPA	1) Question posted on reddit yieled replies from 4565 comments; top 150 replies sourced 2) Comments were copied without usernames and assigned a 5 character alphanumeric ID as provided by the random sequence generator at random.org 3) Transcripts were analysed for general themes in experience, which were then combined into overarching key themes and trends in the sample 4) No mention if independent coders were used for agreement

SP Singh, Z Islam, LJ Brown, R Gajwani, R Jasani, F Rabiee, and H Parsons; 2013
UK
Programme Grants for Applied Research,
Not stated
Explore how service users and their families make sense of psychosis and initiate help-seeking
Nottingham Onset Schedule
Thematic analysis
After a patient had consented to participate in the study, a date, time and location for the interview were agreed between the patient and the researcher. Before the assessment began, patients were asked whether the interview could be digitally audio recorded. If they declined, one of the two researchers present at the interview conducted the interview to complete the schedules and the other made comprehensive notes for later scrutiny. Before appointments, researchers screened medical records to create NOS, EPAS and Encounter timelines. During the interviews, participants were reminded about the reasons for the assessments and any queries/concerns were addressed. Once the sociodemographic data had been collected, the NOS and EPAS were administered. In addition, researchers listened carefully for instances of participants giving spontaneous attributions during the NOS phase of the interview. Finally, help-seeking attempts and pathways to care were determined using the ENRICH encounter form. The same procedure was followed in interviews with carers/informants.

Jens Einar Jansen, Marlene Buch Pedersen, Lene Halling Hastrup, Ulrik Helt Haahr, andErik Simonsen; year: 2015
Denmark
Early Intervention in Psychiatry
Social constructivism
Exploring service users perspectives, including pathways to care; Exploring service users' experience of an early detection service and transition to specialized treatment service, including pathway to care, understanding of illness and barriers to adequate assessment and treatment
Semi-structured interview
Thematic analysis
1) Service users meeting the inclusion criteria were recruited in collaboration with the clinical staff aiming at diversity of age and gender. 2) The interviews lasted half an hour on average and took place either in the clinic or, if preferred by the participants, in their own homes. Five participants chosethe latter option. 3) The same researcher conducted all the interviews. Participants were engaged in a conversation about their pathway to care: How and when the difficulties started, how they initially understood these difficulties and their experienceswith early detection and treatment services. Two members of the research team analysed the data and the first author translated the excerpts used in the paper. 4) The sample size was based on existing relevant literature, but the a priori plan was that if saturation was not reached at the estimated number of participants, recruitment would continue. However, the saturation was reached at 10 participants. 5)The data were organized in the software program NVivo 10.1.2. and analysed according to thematic analysis. The researchers followed Braun and Clarke's (2006) method of analysis, which was divided into 6 phases - digitally recorded interview and transcribed verbatim, repeatedly read by authors, generated initial codes for dataset, gathered themes for codes, refined themes according to internal homogeneity and external

Nina Bay, Jone Bjørnestad, Jan O. Johannessen, Tor K. Larsen and Inge Joa; year: 2016
Norway
Early Intervention in Psychiatry
Not stated
Explore service user perspectives on factors that prevent or delay access to healthcare factors ; 1) To improve knowledge about factors that prevent or delay patients with a long duration of psychosis from accessing psychiatric health-care services at an earlier illness stage 2) To gain knowledge on their personal views on the impact of ongoing informational campaigns (ICs) on help-seeking behaviour
Semi-structured interview
systematic meaning condensation procedure
1) Study eligible participants were consecutively identified for participation in this sub-study2) A semi-structured interview guide was developed and revised by the TIPS research group based upon clinical case descriptions, literature review and pilot interviews3) The interview guide was followed in aflexible manner, focusing on the following maintopics: ‘ symptom awareness’ , ‘ help-seeking behaviour’ , ‘ family and professionals involvement’ and ‘ TIPS ICs awareness and feedback’ . 4) Each theme was introduced with an open-ended question.The questions were followed up depending on how much the participant elaborated. The interviews were conducted by the first author, each interview lasting onaverage for 40 min. All interviews were conducted atthe Stavanger University Hospital. The interviews were audiotaped and transcribed verbatim5) The analysis was performed by two of the author who followed a systematic meaning condensation procedure, to identify the content and variety of the experiences. Researchers thoroughly read through the transcribed interviews to form an impression of the experiences, identified meaning units (defined as a "section of the text that encapsulates one aspect of meaning as it relates to the experience of thei nformant, and is identified by a spontaneous shift in the meaning of the text"), constructed larger categories of themes through the combination of meaning units based on sameness within and beterween intervies, and summarizing the contents of the main categories that were considered most representative

Manuela Ferrari, Nina Flora, Kelly K. Anderson, Asante Haughton, Andrew Tuck, Suzanne Archie, Sean Kidd, Kwame McKenzie, and on behalf of the ACE Project Team; Year: 2018
Canada
Early Intervention in Psychiatry
Not stated
Investigate the role of gender in the pathways to care; To investigate the role of gender in the pathways to care
1) Focus groups 2) Semi-structured individual interviews
Thematic analysis
1) Participants who took part in the ACE Pathways toCare Project were contacted and asked to attend afocus group or interview to discuss pathways to care. They were presented the results of the quantitative study concerning pathways to care and asked to comment on them 2) To include African and Caribbean women’ sparticipation in the study, we adjusted the studyprotocol and undertook in-depth individual interviews 3) In the middle of each focus group and interview researchers shared pathway maps and the preliminary study findings from the ACE Pathways to Care Projects to generate furhter discussions aboutDUP and healthcare services involved in the pathways. 4) 20-30 minutes of debriefing 5) All analytic tools were digitially recorded and transcribed; analysis steps followed Braun and Clarke (2006)

Kate V. Hardy, Caroline E. Dickens, Erika L. Roach, Vicki Harrison, Aakash Desai, Laurie Flynn, Douglas. L. Noordsy, Judith Dauberman & Steven Adelsheim; Year: 2020
USA
Psychosis, Psychological, Social and Integrative Approaches
Not stated
Explore the role of stigma and what, if any, impact it has on help-seeking from individuals with lived experiences of psychosis; To explore how the role of stigma and what, if any, had an impact on the decisions to seek care from the perspective of individuals with lived experience of psychosis and their caregivers
Online qualtrics survey; contained both open-ended and closed questions
Thematic analysis
1) Members of the Lived Experience Workgroup generated an electronic Qualtrics survey consisting of 15 qualitative and quantitative questions regarding experiences of stigma and its impact on accessing care 2) In order to ascertain average DUP, respondents were asked how much time passed between initial symptoms of psychosis and first access to services 3) Respondents were asked a series of closed and open-ended questions related to accessing care, best practices to ensure individuals have information regarding FEP and the experience of stigma and what, if any, influence this had on their decision to disclose symptoms and access treatment 4) Qualitative responses were collated and analyzed using thematic analysis approach (Braun & Clarke, 2006)

Sanna Tanskanen, Nicola Morant, Mark Hinton, Brynmor Lloyd-Evans, Michelle Crosby, Helen Killaspy, Rosalind Raine, Stephen Pilling, and Sonia Johnson; Year: 2011
UK
BMC Psychiatry
Not stated
Investigate service users’ and carers’ experiences on FEP and help-seeking; To investigate service users’ and carers’ experiences of the onset of psychosis and help-seeking
Semi-structured interview
Thematic analysis
1) Participants were recruited via CIEIS clinical staff. Interviews lasted an hour on average and took place at CIEISor respondents’ homes2) Interview transcripts were entered into QSR NVivo7 qualitative analysis software and analysed using thematic analysis

Jens Einar Jansen, Peter Michael Wøldike, Ulrik Helt Haahr, Erik Simonsen; Year: 2014
Denmark
Psychiatric Quarterly
Not stated
Explore service users perspectives on pathways to care; To explore and describe service-users'   perspectives on helpful and unhelpful aspects in their pathway to care, in order to gain a better understanding of barriers to early detection and treatment of psychosi
Semi-structured interview
Thematic analysis
1) Service users were recruited via Opus clinical staff for hour-long interview that took place either at the clinic or in participant's homes 2) Service users' interviews by researcher focused on pathways to care, onset, how they understand their difficulties, and how they came into treatment 3) Data was organized in NVivo 10.0.3. (QSR International, Denmark, Copenhagen) and analysed

Sarah R. Kamens, Larry Davidson, Emily Hyun, Nev Jones, Jill G. Morawski, Matthew M. Kurtz, Jessica Pollard, Gerrit Ian van Schalkwyk & Vinod Srihari; Year: 2018
USA
Psychosis, Psychological, Social and Integrative Approaches
Not stated
Investigate service user perspectives on DUP and lived experiences of FEP; 1) Investigate service users’ subjective experiences and conceptualizations of DUP 2) Compare service-user understandings to those of clinicians 3) Broaden the person-centered research on lived experiences of FEP
Semi-structured interview
Mixed methods data analysis 1) Compared standardized calculations of DUI/DUP with the participants’ subjective perspectives 2) Qualitative analysis utilized a modified version of Giorgi (2009) and Wertz’s (e.g. 2015) systematic phenomenological procedures
1) Potential participants were identified from within the active roster by intake or treatment team members and were invited to participate in a qualitative study 2) All interviews were audio-recorded and later transcribed verbatim

Leopoldo Cabassa, Sarah Piscitelli, Morgan Haselden, Rufina Lee, Susan M. Essock, and Lisa B. Dixon; Year: 2018
USA
Psychiatric Services
Not stated
Understand pathways to care from perspectives of lived experiences of FEP and family; To understand the pathways to care from the onset of psychosis to entry into EIS for individuals experiencing FEP and to develop a grounded model of factors that shaped pathways to EIS
Semi-structured interview
1) Grounded theory 2) Case study methodology
1) Research assistants extracted information from RAISE Connection records to collect information on participants' demographics, onset of psychosis, date of entry into RAISE Connection, type of help-seeking contacts, and use of substances. 2) Interviews were conducted by trained research assistants, audio recorded (except for two documented via interviewers' notes), and professionally transcribed. Family members were interviewed on the phone 3) Extracted data were analyzed using SPSS software. Qualitative data were analyzed using grounded theory and a case study methodology to identify factors that expedited or delayed entry into RAISE Connection. A grounded model emerged from our data depicting factors that shaped help-seeking decisions and either shortened or lengthened pathways to care. Atlas.ti was used to code all qualitative data. Themes were present regardless of whether family members were interviewed or not.

Julie Nordgaard, Lars Siersbaek Nilsson, Karina Gulstad, Marlene Buch-Pedersen; Year: 2020
Denmark
Psychiatric Quarterly
Not stated
Examine help-seeking behavior from service users with FEP; 1) To examine how Cornally and McCarthys’ 5-step model of help-seeking behaviour function in patients with first-episode of psychosis? 2) To examine how psychopathological phenomena in themselves complicate help-seeking behaviour in first-episode psychosis?
Semi-structured interview
Thematic analysis
1) All patients were interviewed between 14 and 30 days after admission or contact to the early detection team 2) The interviews were conducted in a conversational and phenomenologically oriented style focusing on the patients’ lived experiences while following their narratives. Interview materials were based on a lit review, clinical case descriptions, and pilot interviews. 3) All interviews were video filmed and transcribed verbatim 4) To answer research question 1, a bottom-down deductive approach was used; to answer research question 2, a bottom-up (inductive) approach was used. 5) Researcher's analysis steps followed Braun and Clarke's (2006) guide

Eric Macnaughton, Sam Sheps, Jim Frankish and Dave Irwin; Year: 2015
Canada
Psychosis, Psychological, Social and Integrative Approaches
Constructivist
Understand narrative insight development from people with FEP, including help-seeking; To understand the process of narrative insight development in early psychosis from the person’ s perspective
1) Written stories2) Follow-up interview
Integrated narrative analysis within the overarching approach of constructivist grounded theory
1) Researchers asked participants to write a story describing what happened, and how they made sense of their experience prior to entering the mental health system2) Following narrative coding of the written stories, participants were then interviewed in order to ascertain how the individual’ s understanding may have changed upon entering the mental health system3) Data (stories and interview) was included in the constructivist grounded theory analysis

Leanne Bogen-Johnston, Richard de Visser, Clara Strauss, Katherine Berry, and Mark Hayward; Year: 2019
UK
Journal of Health Psychology
Not stated
Explore barriers and enablers to disclosure of voice hearing from perspectives of voice hearers, family, and healthcare professionals ; To explore voice hearing in servicers with FEP about the barriers and enablers to the disclosure of distressing voices to family, friends, and health professionals
Semi-structured interview
Thematic analysis
1) Prior to interview, clinicians discussed the study with service users and offered them a participant information sheet (PIS). Once permission was given interviews were arranged on NHS premises or participants homes 2) Participants completed semi-structured interviews that were open-ended questions to allow self-reflection and exploratory dialogue 3) Interviews were digitally recorded, transcribed verbatim, and anonymized 4) Inductive TA was conducted following Braun and Clarke’ s (2006) six-phase guide

Ryan Melton, Shannon Blajeski, Diana Glasser; Year: 2020
USA
Community Mental Health Journal
Social constructivist
Examine the experiences of DUP from people with psychosis; To examine the experiences of a sample of young adults from the Early Assessment and Support Alliance (EASA) program to learn more about the DUP process
Semi-structured
Grounded theory
1) Flyers were posted at the early intervention programs and interested participants directly contacted teh researchers 2) Confidentiality was explained thoroughly at the time of consent and all participants were assured that the actual early intervention program clinical site would not have access to their interview 3) Semi-structured interviews began with asking about the period when the clients or family member realized there was a mental change, followed by asking questions about the process of searching for help, and ended by asking about the process of beginning to work with the early intervention program 4) Interviews lasted from 30 min to 1 h and were audiotaped, pseudonyms were used and later deleted during the transcription process 5) The de-identified interview transcripts were uploaded into Dedoose software program, version 6.1.18 for analysis 6) Interview transcripts were coded independently and each individual researcher began with an unmarked copy 7) Researchers independently coded themes across all transcripts using an open coding process. After each successive open coding series, the research team met and discussed core theme areas, using an iterative process to reach the core categories. The research team then used individual

Abigail M. Judge, Sue E. Estroff, Diana O. Perkins, David L. Penn; Year: 2008
USA
Psychiatric Services
Not stated
Explore how people with FEP and their family members recognized and responded to early psychosis changes ; To explore when and how individuals responded and recognized early psychosis and how they responded to these changes
2 semistructured interviews
1) Grounded theory 2) Thematic content analysis
1) Onset of psychotic symptoms was established by raters 2) First interview was a semistructured interview designed to elicit an in-depth narrative of participants' subjective experience of early psychosis 3) Second interview was designed to collect data on help seeking 4) Analyses of interview transcripts were conducted by using inductive principles, including grounded theory and content analysis

Appendix B. Full table of participant characteristics

Author, year of publication	**Participants**	**Sociodemographics**
Amanda Spikol and Jamie Murphy; 2019;	Reddit users that eperienced psychosis and have since been diagnosed; top 150 replies sourced	"User demographic information is not required for posting nor made public; therefore, gender, ethnicity and demographic factors were unknown unless a user chose to share that information, though 56% of reddit users are American, 69% are male, and 58% are in the 18-29 age range 45. Sample homogeneity was the experience of psychosis." -- 43 individuals provided their age of initial psychosis awareness, showing a range of 7.5-32 years and mean age of 16.34 (SD=5.63)

SP Singh, Z Islam, LJ Brown, R Gajwani, R Jasani, F Rabiee, and H Parsons; 2013
Patients attending the Birmingham early intervention service (within the BSMHFT) who had a first episde psychosis;
qualitative doesn't have demo information for sample: total number of participants is 25 quanitative-only 45 (34.1%) white 35 (26.5%) black 43 (32.6%) Asian - 9 (6.8%) as ‘ other’ - predmoninantly male (73.5%), were young [20.73 years, standard deviation (SD) 5.53 years], had a psychotic disorder (schizophrenia 68.9%) and were born in the UK (81.8%) - 83.7% of the Asian sample reported having a religious affiliation to Islam - 82.9% of the black sample reported a religious affiliation to Christianity - 64.4% of the white group declared no religious affiliation at all - 74.4% of the Asian participants, 54.3% of the black participants and 15.6% of the white participants practiced a religion - Deprivation levels: Whole sample falling into the bottom 40% of national deprivation levels. About two-thirds (68.3%) of the Asian sample were in the bottom 10% in comparison to 50.0% of the black sample and 35.6% of the white sample.

Nina Bay, Jone Bjørnestad, Jan O. Johannessen, Tor K. Larsen and Inge Joa; year: 2016	**Jens Einar Jansen, Marlene Buch Pedersen, Lene Halling Hastrup, Ulrik Helt Haahr, andErik Simonsen; year: 2015**
Service users part of ‘ Treatment and Intervention in Psychosis Study’ (TIPS-2) that met the criteria with a DUP lasting 6 months or longer and have met the DSM-IV criteria for first-episode schizophrenia, schizophreniform disorder, schizoaffective disorder, brief psychotic episode, delusional disorder, drug-induced psychosis, affective psychosis with mood incongruent delusions, or psychotic disorder not otherwise specified; total: 8	Service users that have met the criteria for non-affective psychotic disorder (schizo-phrenia, delusional disorder, acute or transientpsychosis, schizoaffective psychosis, induced psy-chosis or unspecified non-organic psychosis), have accessed psychiatric services through the early detection team (TOP); were currently enrolled in a specialized early psychosis treatment service (OPUS) as a first treatment for this disorder, and had
1) 4 women and 4 men from the ongoing TIPS-2 study were interviewed2) Included both students and full-time employees, with age ranging from 17 to 44 years	Ten service users with a median age of 21 (range18–27), five males and five females and all had an ethnic Danish background - Seven lived independently two lived with their parents, and one in supportive housing - All participants had started first treatment for psychosis within the last 3 years (median 19.5 months, range 5–30) - 20% primary education, 60% seconday education, 20% higher education - 40% were absent from education or work due to illness, 20% students, 20% part-time, 20% unemployed

Jens Einar Jansen, Peter Michael Wøldike, Ulrik Helt Haahr, Erik Simonsen; Year: 2014	**Sanna Tanskanen, Nicola Morant, Mark Hinton, Brynmor Lloyd-Evans, Michelle Crosby, Helen Killaspy, Rosalind Raine, Stephen Pilling, and Sonia Johnson; Year: 2011**	**Kate V. Hardy, Caroline E. Dickens, Erika L. Roach, Vicki Harrison, Aakash Desai, Laurie Flynn, Douglas. L. Noordsy, Judith Dauberman & Steven Adelsheim; Year: 2020**	**Manuela Ferrari, Nina Flora, Kelly K. Anderson, Asante Haughton, Andrew Tuck, Suzanne Archie, Sean Kidd, Kwame McKenzie, and on behalf of the ACE Project Team; Year: 2018**
Participants that met the requirements needed for ICD-10 criteria for schizophrenia spectrum disorder (F20-29, except F21), had previously had not	Service users and carers from Camden & Islington NHS Foundation Trust Early Intervention Service (CIEIS). Researchers prioritized service users that were in contact with community organizations at the time of referral, as well as seeking out diverse	193 participants; 41 service users with lived experience of psychosis; 135 family members, 8 people with indirect experience. All resided in the US.	25 service users of EI services from African-origin, Caribbean-origin and European-origin populations. Part of the ACE Pathways to CareStudy – a large, comparative, mixed methods study of pathways to EI services in the cities of Toronto and Hamilton in the Province
1) 11 service ages, median age of 20 2) 6 males and five females 3) All ethnic Danish background	1) 21 service users, 9 carers 2) 6 female, 15 male3) Mean age = 23.5 4) Ethnicity: White British (n=3 respondents; overall CIEIS= 41%); White Other (n=4 respondents; overall CIEIS= 14.2%); Black African (n=3 respondents; overall CIEIS= 14.2%); Black Caribbean (n=5 respondents; overall CIEIS= 5.8%); Asian Bangladeshi (n=4 respondents; overall CIEIS= 7.4%); Mixed Race (n=2 respondents; overall CIEIS= 7.5%)5) <DUP 3 months = 10/21 (48%) respondents; 48/117 (41%) overall CIEIS	No personal or demographic details were requested from participants and individuals were assured of confidentialit	1) 12 women (African= 2,Caribbean= 1 and European = 9) 2) 13 men (African = 3, Caribbean = 3 and European= 7) 3) Mean age of 26 year-old 4) 21 participants self-identified as heterosexual, one as homosexual,and three as bisexual 5) 17 were born in Canada, 8 outside Canada 6) 8 completed less than high school education; 17 completed high school or higher levels of formal education 7) Women reported depression ,anxiety, self-harm and suicidal ideation as reasons for seeking help, first point of contact was outpatient psychiatrist (n=4), GP (n=4), ED (n=4) 8) Men reported seeking help for active symptoms of psychosis, relationship problems, and substnace abuse and stress; first point of contact was GP (n=6), outpatient psychiatrist, social worker (n=4), ED (n=1), and police and criminal justice system (n=2)

Leanne Bogen-Johnston, Richard de Visser, Clara Strauss, Katherine Berry, and Mark Hayward; Year: 2019	**Eric Macnaughton, Sam Sheps, Jim Frankish and Dave Irwin; Year: 2015**	**Julie Nordgaard, Lars Siersbaek Nilsson, Karina Gulstad, Marlene Buch-Pedersen; Year: 2020**	**Leopoldo Cabassa, Sarah Piscitelli, Morgan Haselden, Rufina Lee, Susan M. Essock, and Lisa B. Dixon; Year: 2018**	**Sarah R. Kamens, Larry Davidson, Emily Hyun, Nev Jones, Jill G. Morawski, Matthew**
20 purposively selected EIP service users that were currently experiencing voices and had been doing so for at least 3 months	12 participants who were currently engaged in the EPI program and who were judged by the clinician researcher as being clinically stable and having	9 patients with first-episode psychosis b	Clients enrolled in RAISE Connection, a specialty-care program that uses a critical-time intervention framework; total: 20 clients, 10 family members	10 Service users at an EIS program in Connecticut, part of a larger STEP-Early Detection (STEP-ED) study
1) 12 men; 8 women 2) Mean age= 25 (SD=4.7); age range: 19 - 35 3) Age of voice onset = 6 to 32 years (Mean= 19 (SD=6.8) Mdn= 19) 4) Voice duration less than 1 to 21 years (Mean= 7 (SD= 6.8) Mdn= 3)	1) 12 participants were evenly split by gender2) 2 (17%) had schizoaffective disorder; 3 (25%) had schizophrenia; 4 (33%) had psychosis (not otherwise specified); 3 (25%) had bipolar disorder with prominent psychotic features3) Ages ranged between 20 and 32, with the median age being 26 years4) Participants had typically been in the mental health system or been diagnosed 7 months prior to study participation, ranging from 2 to 36 months5) 7 (58%) of the participants had not experienced a second psychotic episode; 5 (42%) had experienced at least one relapse; 2 (17%) had never been hospitalized; 8 (67%) were from the Day Program; 4 (33%) were from the Community		1) 9 participants (45%) were female 2)11 (45%) were Hispanic, 5 (25%) were African American, 2 (10%) were non-Hispanic white, and 2 (10%) were Asian 3) Mean age =23.7±4.4 years; mean age at onse= 20.6 years±4.1; mean age at entry into RAISE= 21.3 years old±4.2. 4) 8 family members were female (80%) and mothers (80%).	1) four females, six males 2) mean age = 22.5 years, age range: 19–26 years 3) Half of the sample (five participants) were within two months of intake to the program, and half of the sample (five participants) had received at least one year of EIS 4) 2 identified as African-Ameriacn, 3 mixed-race, 4 as white

Abigail M. Judge, Sue E. Estroff, Diana O. Perkins, David L. Penn; Year: 2008	**Ryan Melton, Shannon Blajeski, Diana Glasser; Year: 2020**
15 adults referred through clinicians in a public outpatient psychiatry clinic that met the critiera for DSM-IV Axis I Disorders	9 clients with FEP that met the diagnosis of psychosis present for less than 2 years (e.g. psychosis, NOS; schizophrenia; schizoafective disorder), age 18–30, and involved in the early intervention program for at least 6 months at the time of the interview; including the family members, total of 15 interviews
7 had schizophrenia (47%), 5 had schizoaffective disorder (33%), 2 had schizphreniform disorder (13%) and 1 had psychotic disorder NOS (1%) - 8 male; 7 female - Mean age= 24.4±5.28 - 12 caucasian (80%), 2 African-American (13%), 1 Asian (1%) - 13 single or never married (87%) - DUP averaged 21.7±31.1 months (median 11; mode 12)	1) Mean age= 24 2) DUPmean= 4.1 months

Appendix C. 19-item Critical Appraisal Checklist for quality appraisals

Checklist (American Psychological Association, 2018; NICE, 2012) with 3 additional concepts related to meta-ethnography aims**:**

- Study identification
- **Abstract:**
    - **Are funding and/or sources of conflict clearly acknowledged?**
    - *Does the abstract adequately describe the study's aims, designs, and main implications and/or significance?*
    - Is there an abstract?
    - Does the abstract state the question/objective?
    - Does the abstract adequately describe the study design?
    - Does the abstract list the analytic strategy?
    - Does the abstract list the main implications and/or significance?

- **Theoretical approach 1.1 :**
    - Is a qualitative approach appropriate?
    - Is a rationale given for using a qualitative approach?
    - Is it clear how prior understandings of the phenomena under study were managed and/or influenced the research*?*
- **Theoretical approach 1.2 :**
    - Is the study clear in what it seeks to do?
    - Does the study have a clear rationale and aim?
    - Is the approach to inquiry clear?

- **Ethics:**
    - How clear and coherent is the reporting of ethics?
- **Concepts 2.1:**
    - Is psychosis defined?
- **Concepts 2.2:**
    - Is help-seeking defined?
- **Concepts 2.3:**
    - Is first episode psychosis defined?
- **Study design:**
    - How defensible/ rigorous is the research design/methodology?
    - Is the choice of method clearly described?
    - Is the design appropriate to the research question?
    - Are there clear accounts of the rationale/justification for data collection and data analysis *techniques used?*
    - Is the selection of cases/sampling strategy theoretically justified?
    - Are intended participants clearly defined?
    - Is the recruitment process clear?
- **Data collection:**

    - How well was the data collection carried out?
    - Is the data collection strategy clear?
    - Were the appropriate data collected to address the research question?
    - Were the mean and range of time duration for interviews and other data collection tools clear/appropriate?
    - Is the procedure reliable/dependable?
    - Were coders and analysts and their training clearly described?
- **Trustworthiness 3.1:**
    - Is the role of the researcher clearly described?
    - Is the role of the researcher clearly described?
    - Does the paper describe how the research was explained and presented tothe participants?
    - Has the relationship between the researcher and the participants been adequately considered?
    - Was researcher bias considered?
- **Trustworthiness 3.2:**
    - Is the context clearly described?
    - Are sampled participants clearly defined?
    - Are the demographics and/or cultural information, perspectives of participants, or characteristics of data clear and appropriate
- **Trustworthiness 3.3:**
    - Were the methods reliable?
    - Was data collected by more than 1 method?
    - Do the methods investigate what they claim to?
- **Analysis 4.1:**
    - Is the data sufficiently rigorous?
    - Is the process of analysis clear?
    - Is it clear how the themes and concepts were derived from the data?
    - Is the procedure reliable/dependable?
- **Analysis 4.2:**
    - Is the data 'rich'?
    - Has the researcher discussed contradictory data (or suggested why there is none)?
    - How well has the detail and depth been demonstrated?
    - Are responses compared and contrasted across groups/sites*?*
- **Analysis 4.3:**
    - Is the analysis reliable?
    - Were softwares that were used indicated?
    - Did more than 1 researcher theme and code transcripts/data?
    - Did the researchers make clear how differences, if at all, would have been resolved?
- **Analysis 4.4:**
    - Are the findings convincing?
    - Is the reporting clear and coherent?
    - Are the findings convincing?
    - Were findings clearly presented?
    - Are the research findings compatible with the study design?

    - Are extracts from the original data included?
- **Analysis 4.5:**
    - Are the findings relevant to the aims of the study?
    - Were the findings grounded in theevidence?
    - Did the data adequately capture forms of diversity most relevant to the question, research goals, and inquiry approach?
- **Conclusions:**
    - Are the conclusions adequate?
    - Were similarities and differences from prior theories and research findings identified?
    - Did researchers make clear how findings were or can be best utilized?
    - Were any reflections made on alternative findings?
    - Have alternative explanations been explored and discounted?
    - Does this enhance understanding of the research topic?

Appendix D: Table with descriptive quality appraisals of each study :

Study identification	author: Amanda Spikol and Jamie Murphy
Are funding and/or sources of	Yes
Abstract:	Yes; the abstract is written clearly, states the question/objective, and lists the study design as an internet-based IPA study. The results and conclusion section of the abstract lists the significance of these results and how they may be used to understand early psychosis experiences
Theoretical approach 1.1 :	Yes; clear rationale given for using a qualitative approach and authors justify reasons for conducting a study using self-reported qualitiatve responses online as opposed to conducting an interview (e.g. researcher bias). Some justification for IPA, however more information could have been helpful
Theoretical approach 1.2:	Study has clear rationale, aim and approach to inquiry is clear
Ethics*?*	Ethics is not mentioned at all; Reddit was contacted for data use permission. Ethical approval may not be necessary in using
Concepts 2.1	No
Concepts 2.2	No
Concepts 2.3	No
Study design	Choice of method is clearly described and an IPA is appropriate to the research qusetion. However, very little information is given on data collection techniques apart from how reddit was sorted and top comments were listed (not clear if that's what their sample is based off of), which makes sampling strategy unclear and difficult to justify. Intended participants are somewhat
Data collection:	Intention of data collection strategy was clear (self-reported reddit comments) but it is not clear how researchers ensured that appropriate data was collected to address research question or how they sorted comments to the most appropriate posts. Top comments was mentioned but was not clear if they were describing the reddit set-up or if this was their strategy. As such, the
Trustworthiness 3.1 :	Role of the researcher purposely not being involved with the participants is clear and research bias was considered
Trustworthiness 3.2:	Sampled participants are not clearly defined as demographic data was not captured. Context cannot be clearly described if data
Trustworthiness 3.3:	Only self-reported data was collected so it is unclear if the method investigated what they claim to
Analysis 4.1:	The description of the analysis is clear, however is unclear if researchers were analyzing them, if there was more than one researcher, if differences arose in interpretations and how they were resolved and so on. Researchers vaguely described how
Analysis 4.2:	Researchers demonstrated detail and depth well and compared and contrasted responses between participants, describing minor symptoms as well (which I believe is part of the contradictory data).
Analysis 4.3:	Softwares used not mentioned, if at all, and should have been made clear what analysis tool was used. It is unclear of more than one researcher them and coded the data or how researchers resolved differences. It is diffcult to conclude that the analysis is reliable.
Analysis 4.4:	Findings are somewhat convincing. Researchers only sent me the study before it underwent peer review so some tables are missing and therefore not clearly presented in some sections. However, extracts are included and findings and its limitations are comptaible with the study design.
Analysis 4.5:	Findings were grounded in evidence and the data researchers described captured diverse data relevant to the question and study aims
Conclusions:	Researchers made clear in their discussions the similarities and differences from prior literature to the study's findings. They also made it clear what their recommendations for future research are. Reflections were made on alternative findings as well and alternative explanations were not explored or discounted as this was an exploratory study. Overall, this enhances the understanding of the research topic.

author: SP Singh, Z Islam, LJ Brown, R Gajwani, R Jasani, F Rabiee, and H Parsons
Yes
Yes; the abstract is written clearly however as it is a mixed-methods study and there are three different studies, there two abstracts: Abstract for the mixed-methods study and another abstract for Study 1 (which is what is being investigated in this meta-ethnography). The abstract states the question/objective and study design and that a qualitative analyses was used.
A clear rationale was given for using qualitative research and the authors listed several examples, including conducting a systematic review to demonstrate the importance of conducting a qualitative study with this population group. They made clear how prior understandings of FEP and help-seeking has influenced their study.
Study 1 has a clear rationale and aim. Approach to inquiry (Mixed-method approach) was clear. However it would have been
Clear on ethical approval, informed consent, and participant distress; unclear on the methods taken to anonymize participant
No
Yes
Yes; not clearly defined however but makes clear that FEP means "first presentation of psychotic illness"
Coice of method for Study 1 is clearly described and the design is appropriate to the research questions. There are clear accounts of the rationale and justifcation for data collection and quantiative data analysis techniques used in the context of using a mixed-method approach. However, the study could have benefited more if more justification was given for the use of a thematic
Data collection strategy was clear and appropriate data was collected to address the research question. The mean and range of time duration for interviews were clear and tools used were appropriate when listed. The procedure is reliable. The procedures of the coding and analyzing was clearly described.
The role of the researcher is clearly described and the study described how the research was prevented to the participants. Researcher bias was considered however the relationship between researcher and participants, as well as how diferent healthcare
Sampled participants are clearly defined in the study, with the demographics, cultural information, perspectives and related data
Methods were both quantiative and qualitative and they investigated what they claimed to
The process of analysis was clear and the researchers listed not only the procedure of capturing data but the procedure of analyzing qualitiatve data
Data is rich; researcher discussed contradictory data and listed the reason why when describing the procedure of TA. Researchers demonstrated detail and depth in their findings and compared their responses across different groups within the
Softwares that were used were indicated and more than one researcher coded and themed transcripts/data. They also listed using consensus coding to resolve differences and reduce bias
The reporting is clear and coheren and findings were convincing and clearly presented. The research findings were compatible with the study design and researchers included extracts from the original data in their results
Findings were relevant to the aims of the study as they were grounded in evidence and adequately captured forms of diversity most relevant to the questions, research, goals and inquiry approach
Similarities and differences from prior theories and research findings were identified. Researchers made it clear how the findings can be further explored and used.

author: Jens Einar Jansen, Marlene Buch Pedersen, Lene Halling Hastrup, Ulrik Helt Haahr, and Erik Simonsen
Yes
Yes; abstract is written in a clear way reporting the question/objecitve and study design. Analytic strategy was not mentioned or listed but the abstracted listed the main implications and/or signifcance
Yes; clear rationale given using qualitative approach and researchers made it clear how prior understandings of DUP and FEP helped influence the management and ratiole of the current study **Theoretical approach:**
The study has a clear rationale and aim and that it is a qualitative study but the approach to inquiry is not clear until the study reaches the Analysis section.
Clear on ethical approval, informed consent, and participant distress; unclear on the methods taken to anonymize participant
Yes
Yes
Yes
Some elements of the study design are both clear and vague, which reduces the rigorousness of the design/methodology. It is a semi-structured quaulitative analysis however researchers did not provide a clear account of the rationale and justification for data analysis techniques apart from stating what they used. However, data collection techniques used were clear in how semi-
Data collection is clear and appropriate data was collected to address research question. Researchers also listed the mean and range of time duration for interviews and other data collection tools. The procedure is relaible and roles of the coders and analysts were clearly described.
Roles of the researcher were clearly described in both the procedure and the analysis. It was not clear how the study was explained and presented to the participants however the list of questions participants were asked were clearly reported and listed.
Context was described to a certain extent. Sampled participants were somewhat defined. Gender, ethnicity, acommodation and employment status, and education was listed but the mean age of participants was not; the median age was reported. The
Methods were reliable. A semi-strucutred method was the only method used; however, it was designed based on previous
The data is sufficiently rigorous; process of analysis is clear, as well as how themes and concepts were dervied from the data. The procedure is reliable and dependable.
The analysis was rich to a certain extent; contradictory data was not provided and researchers did not make a statement of how they would use data that does not make up the majority. However they did list in the results how many participants made up each
The analysis is reliable; software that was used were indicated, more than 1 researcher coded and themed the data and they clearly listed how differences between researchers would be resolved.
Findings are convincing and the reporting is clear, coherent, and clealy presented. Research findings were compatible with the study design and extracts from original data included. However it is unclear if the contradictory data was examined, discarded, utilized in a different study, etc.
Fingds were relevant to the aims of the study; it captured data that was most relevant to the question
Conclusions are adequate to a certain extent; similarities and difference from prior theories and research findings were identified and researchers provided different ways the findings can be used for further research. Alternative findings were not reflected upon and it is unclear if and how they were used. Overall, this does enhance the understanding of the topic however it is a limitation of the study to report just how many participants had similar understandings of FEP without clarifying what the alternative understandings are.

author: Nina Bay, Jone Bjørnestad, Jan O. Johannessen, Tor K. Larsen and Inge Joa
No
Yes; abstract clearly states the question, objective, study design, and analytic strategy. It also lists the main implications and/or significance.
Yes; a clear rationale is given for using a qualitative approach and it is clear how prior understandings of the phenomena under study were managed and/or influenced by the research.
Yes the study is clear on what it seeks to do as the rationale and aim is clear. The approach to inquiry is also clearly justified.
Clear on ethical approval, informed consent, and participant distress; unclear on the methods taken to anonymize participant
Yes
No
Yes
Research design is rigorous to a large extent; choice of method is clearly described and the design is appropriate to the research question. Choice of method, design, and research question were justified, as well were the data collectiontools and analysis used. The selection of cases/sampling strategy was also theoretically justified and intended participants were clearly defined.
Data collection was carried out well to a certain extent. The procedure is not clear, however, appropriate data was collected to address the research question. THe mean and range of time duration of the data collection (e.g. interview) was also clear and carried out well and ethically. Procedure however may not be reliable because the recruitment process is too vague to be
The role of the researcher was described clearly to a certain extent. It was not clear how the research was presented to participants or how researcher bias was considered. However, the role of researcher in the analytic procedure and the interviews
Sampled participants were not clearly defined. Gender was clearly listed, but for age and employment status researchers only listed that participants were in the 17-44 age range and were a mix of students and employees. There was no justification as to
Methods were reliable, even though data was collected by only 1 method. The methods investigated what they claimed to.
The data is sufficiently rigorous; the process of analysis is clear, as well as how themes and concepts were derived from the data.
The data is rich; researchers mentioned contradictory data and responses were compared and contrasted. The data was also rich because of the depth and detail the researchers demonstrated in their results.
The analysis is reliable to a large extent. While it is unclear if software were used or not but, more than 1 researcher themed and coded the transcripts. However, it is not clear how differences if at all would have been resolved between them or if researcher bias was considered.
The findings are convincing; they were clear, coherent, and clearly presented. The research findings were compatible with the study design and the researchers included extracts from the original data.
The findings are relevant to the aims of the study to a certain extent; The lack of demographic information and the very large age-range makes it difficult to conclude how relevant the findings were as it is presumed that 17-44 has several developmental milestones which may have affected the study's results. However, the data collected answered the research question.
Conclusions were adequate to a certain extent; researchers were able to pull similarities and differences from research findings, included contradictory data and described them, and explored the finding implications and suggestions for future research. However, the age range is far too large to confidently state that the conclusions are adequate. The lack of demographic information is the study's major limitation, as we are unsure of the mean age and its role in the study's findings. The researchers also did not justify why the mean age was not included. This does however enhance the understanding of the research for overall

author: Manuela Ferrari, Nina Flora, Kelly K. Anderson, Asante Haughton, Andrew Tuck, Suzanne Archie, Sean Kidd, Kwame McKenzie, and on behalf of the ACE Project Team
Yes
Yes; the abstract states the question/objective and design. The analytic strategy is not listed, but the abstract lists the main implications and/or significance.
Yes; a rationale is given for using a qualitative approach and it is clear how prior understandings of the phenomena were managed and/or influenced the research.
Yes; approach to inquiry is clear and a justification was provided for using it. The study had a clear rationale and aim.
Clear; ethical approval was gained and participants were informed of the study.
No
No
No
The research design is rigorous; choice of method is clearly described and the design is appropriate to the research question. There are clear accounts of the rationale for data collection and data analysis techniques used. The selection strategy, intended participants, and recruitment participants are clear.
The data collection was carried out well. The data collection strategy was clear and the appropriate data was collected to the address the research question. The mean and range of time duration for interviews were appropriate. The procedure is dependable, even though the coders and analysts roles were not clearly described.
The role of the researcher is described very clearly in data collection, e.g. how and who introduced participants to the research, but not data analysis. There was no mention of what role the reseachers had in the data analysis or if there was more than one.
Context is clearly described, sampled participants are clearly defined and the demographics and cultural information provided are clear and appropriate
The methods were reliable. They investigated what they claim to and researchers reported very clear changes that were made to
Yes; process of analysis is clear and it is clear how the themes and concepts were derived from the data. The procedure is reliable.
The data is rich, however more information could have been provided and/or themes could have been expounded on. The researcher did not discuss contradictory data within gender groups but did discuss and compare responses across both gender
The analysis is only somehwat reliable. The procedure for a TA strategy is clear. However, the resarcher's roles in the procedure of the analysis is not; it is not clear which members of the large research team analyzed the data, if more than 1 researcher analyzed the data, and how differences, if there were any, resolved.
The findings are convincing. The reporting is clear and coherent and clearly presented. The research findings were comptaible with the research design and extracts from the original data were included.
The findings are relevant to the aim of the study and the data adeqately captured forms of diversity most relevant to the question, research goals, and inquiry approach.
Conclusions were adequate. Researchers discussed similarities and differences from prior theories and research findings. They also made it clear how findings can be best utilized or used for further exploration in research. However, as researchers did not mention any contradictory data, there were no altnerative explanations that were explored and discounted. Overall, this enhances the understanding of the research topic.

author: Kate V. Hardy, Caroline E. Dickens, Erika L. Roach, Vicki Harrison, Aakash Desai, Laurie Flynn, Douglas. L. Noordsy, Judith Dauberman & Steven Adelsheim
Yes
Yes; the abstract clearly states the question/objective, study design, analytic strategy, and lists the main implications and/or significance.
Yes; there is a rationale for using a qualitative approach and it is clear how prior understandings of the phenomena were managed and/or influenced the research.
Yes; the study has a clear rationale and aim and the approach to inquiry is clear.
Somewhat clear; lists IRB as approving the study which is ethical approval in the States. However, this is not clarified in the
No
No
No
The design is rigorous. The choice of method is clearly described and the design is appropriate to the research question and study's aims. However, not all techniques were justified, rather described and stated. Intended participants and recruitment process is clear.
The data collection was somewhat clear; since this is an internet study, the researchers described in detail tools used to access participants and how they were analyzed. However it is not clear how the researchers designed their qualitrics survey questions and if this was based on prior literature on pathways to care, stigma, and lived experiences of FEP. This creates doubt in just
The role of the researcher is clearly described from recruitment to data collection to analysis; the relationship between researcher and participants has also been adequately considered and researchers noted the steps they took to reduce researcher bias.
The context is not clearly desscribed. The researchers purposely did not capture demographic data, therefore it is unclear who from the Lived Experience group was interviewed apart frome their role as either service user or caregiver
Yes; the data was collected by more than 1 method and investigated what they claim to.
Yes; the process of analysis is clear and it is clear how the themes and concepts were derived from the data.
Data is rich; researcher discussed contradictory data and demonstrated enough depth in their results. They also compared and contrasted between different types of stigma and how it functioned in treatment delay and help-seeking between people living
Yes; it was indicated that coding was done manually, more than 1 researcher themed and coded the data, and how they attempted to reduce researcher bias and seek consensus.
The findings are only somewhat convincing. Although the research findings are compatible with the study design, the reporting is not very clearly presented and looks disorganized in certain sections of the report. Even though extracts from the original data was included, it was only really cleared up in the discussion section to what extent both caregivers and service users gave the same answers in their surveys.
The findings were relevant to the aim of the study, however they did not capture demographic data and it is unclear how large the age range was of the over 100+ people that responsed. Although this was done purposely by the design, I believe it was a major limitation and design flaw.
Conclusions were adequate. The similarities and differences prior theories were listed and discussed and the researchers made it clear how the findings could be utilized and explored in the future. Overall, this does enahnce the understanding of the research topic however to a certain extent. The sociodemographic data of participants and distinguishing service user and caregiver should have been much cleare in the results.

author: Sanna Tanskanen, Nicola Morant, Mark Hinton, Brynmor Lloyd-Evans, Michelle Crosby, Helen Killaspy, Rosalind Raine, Stephen Pilling, and Sonia Johnson
Yes
Yes; the abstract clearly states the question/objective, study design, analytic strategy, and lists the main implications and/or significance.
Yes; a clear rationale is given for using a qualitiatve approach and it is clear how prior understandings of the phenomena managed and/or influenced the research.
Yes; the study has a clear rationale and aim. The approach to inquiry [thematic] is clear in the analysis and abstract
Not clear; did not state if paper was approved by an ethical committee, if informed consent was used and if participants were
No
No
No
Design is rigorous; design is appropriate to the research question, there are clear accounts of the rationale/justification for data collection and analysis. The selection of sampling strategy is clear and intended participants are clearly defined. Furthermore, the recruitment process is clear.
Data collection was carried out well; the data collection strategy was clear and appropriate data was collected to the address the research question. The researchers also noted how long the interviews lasted on average and coders were described. This is a reliable procedure.
The role of researchers are clearly described. The paper does not describe how the research was explained and presented to participants, however it is clear which members of the research team conducted the interviews and who analyzed them. This
Context is clearly described; sampled particpiants are defined and appropriate demographics and/or cultural information of participants and participant characteristics were captured
Methods were reliable; data was collected by a team of researchers and methods investigated what they claimed as set out in the
Data is sufficiently rigorous; process of analysis is clear and it is clear how the themes and concepts were derived from the data. The analytic procedure is reliable.
Data is rich; researcher discussed contradictory data, compared and contrasted responses between service user and carer and demonstrated detail and depth well.
Analysis is reliable; software used were indiciated and more than 1 researcher themed and coded data. It is implied that "team discussion" helped resolve any differences that emerged however, it would have been better if it was clearly reported.
Findings are convincing; the reporting is clear an coherent and findings were clearly presented with original data extracts included. The research findings are compatible with the study design.
Findings are relevant to the aims of the study; they are grounded in evidence and capttured adequate forms of data most relevant to the research question and aims.
Conclusions were adequate; researchers explored similarities and differences from prior theories and reserach findings, they made clear how findings were or can be best utlizied, and they included contradictory data in a way that further enhances the

author: Jens Einar Jansen, Peter Michael Wøldike, Ulrik Helt Haahr, Erik Simonsen
Yes
Yes; although it does not state the analytic strategy, the abstract states the objective, design, and main implications and/or significance.
Yes; rationale for using a qualitative approach is clearly stated and it is clear how prior understandingds and research on FEP influenced the research.
The study is clear on what it seeks to do and approach is inquiry is clear.
Ethical approval, consent, and debriefing is clearly reported. However, it is not clear how data was protected and anonymized if
Yes
No
No
Design is rigorous; choice of method is clearly described and the design is appropriate to the research question. There are also clear accounts for rationale/justification for data collection and data analysis techniques used. The selection strategy and intended participants are clearly defined. The recruitment process is also clear.
The data collection was carried out well; clear data collection strategy and appropriate data was collected to the address the research question. The mean and range time of duration was listed an appropriate. The coders were clearly described. The procedure of data
The role of the researchers are clearly described in terms of how research was explained and presented to participants, describing which roles the researcher had in interviews and analysis. It is implied that researcher bias was considered by including 3
The context is only somewhat clearly described. Sampled participants are only reported on their median age, which is a limitation since the age range provided of 17-24 has significant developmental milestones that may impact their perspectives
Methods are reliable even though only semi-structured interviews were used. The method investigated what they claimed to in
Data is sufficiently rigorous; the process of analysis is clear and it is clear how the themes and concepts were derived from the data. This makes the analytic procedure reliable.
Data is rich; contradictory data was discussed, responses were compared and contrasted across participants, and the detail and of the data is demonstrated.
The methods are reliable; softwares used were indicated, more than 1 reseracher coded and themed the data, and it was implied how researchers resolved the differences, however it could have been made clearer. **Analysis:**
Findings are convincing; the reporting is clear, coherent, and findinds were clearly presented. The research findings are compatible with the study design and extracts from original data were included.
The findings are somewhat relevant to the aims of the study. While the results were grounded in evidence, having such a large age range and only reporting the median indicates that the sample being described may not be representative of groups of people having FEP as these samples may have been mostly adolescents, young adults, etc. and same for their relatives.
Conclusions were adequate; similarities and differences from prior theories and research findings were identified and reflections were made on alternative findings. Researchers also made it clear how these findings can be best utlizied in future research and exploration. Overall, this enhances the understanding of the topic.

author: Sarah R. Kamens, Larry Davidson, Emily Hyun, Nev Jones, Jill G. Morawski, Matthew M. Kurtz, Jessica Pollard, Gerrit Jan van Schalkwyk & Vinod Srihari
Yes
Yes; the abstract states the question/objective, designs, a mixed-method analytic strategy, and lists the main implications and/or significance.
Yes; a rationale for using a mixed-emthod approach is given and it is clear how prior understandings of both quantitative and qualitatie research influenced the current study.
Yes; the study has a clear rationale and aim and the approach to inqury is clear.
Clear
No
No
No
Design is rigorous; choice of method is clearly described and is appropriate to the research question. Data collection techniques and analysis is also clear with intended participants clearly defined. Recruitment process is also clear
Data collection strategy was clear to a certain extent; appropriate data was collected to the research question but the procedure is only somewhat reliable as it is unclear if the researchers themselves conducted the interviews or not and if the interviewers were also the coders analyzing the data. The mean range of time duration of the interviews were clear and appropriate.
The role of the researchers are somewhat described clearly. The role of the researcher in the analysis is clear and researcher bias is considered, however it is unclear what the researchers roles are in the interviews.
Context is clearly described; sampled participants are clearly defined and the demographics of participant characteristics were clear and appropriate
Methods were reliable; included both quantiative and qualitative methods and both investigated what they claimed to
Data is sufficiently rigorous; the process of analysis was clear in how themes and concepts were derived from the data. The analytic procedure is reliable.
The data is rich; researcher discussed contradictory data, compared and contrasted responses, and demonstrated detail and depth in discussing the findings.
The analysis was reliable; more than 1 researcher themed and coded the data and researchers made it clear that they used a consensus method to resolved differences. Softwares were not reported for neither quantiative or qualitative.
Findings are convincing; reporting is clear, coherent, findings were clearly presented. and extracts from the original data included. It would have better if TSD was defined in a cleare manner. The research findings are compatible with the study design.
The findings are relevant to the aims of the study; the findings were grounded in evidence and the data adequately captured data most relevant to the question and aims of the study.
Conclusions were adequate; similarities and differences from prior theories and research findings were identified. Researchers also reflected on alternative findings and made it clear how these findings can be best utilized in further research, as well as clinical implications. Overall, this enhances the understanding of the research topic.

author: Leopoldo Cabassa, Sarah Piscitelli, Morgan Haselden, Rufina Lee, Susan M. Essock, and Lisa B. Dixon
Yes
Yes; the abstract clearly states its aim, design, analytic strategy, and it lists the main implications and/or significance.
Appropriate but vague; very briefly reported, a rationale is provided for using a qualitative approach and prior studies were briefly reported that influenced the current study. However, more information on grounded theory and case study methdology would have been more helpful in justification its use in the method.
Yes; the study has a clear aim and rationale and explicitly states its approach it inquiry.
Clear on approval and consent; not clear on how identifiable details were protected or changed.
No
Yes
No
Design is rigorous; choice of method is clearly described and the design is appropriate to the research question. There are clear accounts as to why and how data collection techniques were used and the selection strategy was justified. Intended participants were clearly described and the recruitment process was clear.
Data collection was carried out well; the data collection strategy was clear and appropriate data was collected to address the research question. The mean and range of time duration for interviews were clear and appropriate and coders and analysts on the data.
The role of the researchers were clearly described in the recruitment, data collection, and data analysis process. The study described how the research was presented to the participants and consideration of researcher bias was implied but not explictly
Context is clearly described; sampled participants are clearly defined and the demographics and participant characteristics data were clear and appropriate
Methods were reliable; both quantiative and qualitative methods were used and the methods investigated what they claimed to.
Data was sufficiently rigorous; the process of analysis was clear, including how themes and concepts were derived from data. This makes the analytic procedure reliable.
Data is rich; researchers discussed a broad array of participant responses within each theme and found commonality in between them in their comparisons. The detail and depth of the data was demonstrated well.
Methods were reliable; researchers purposely triangulated their methods. Also, more than 1 researcher themed and coded the data, softwares used were indicated, and how differences were resolved were stated in the article.
The findings are convincing; the reporting is clear, coherent, and findings are clearly presented with extracts from the original data included (both in results section wher mostly statements were made, but the appendix provided provided more detailed extracts). The findings were compatible with the study design.
The findings are relevant to the aims of the study; the findings were grounded in evidence and the data adequately captured forms of diversity most relevant to the research question and aims of the study.
Conclusions were adequate; similarities and differences from prior research findings were identified and they discussed contradictory data. They also made clear how findings could be best utilized in future research. Overall, this enhances the

author: Julie Nordgaard, Lars Siersbaek Nilsson, Karina Gulstad, & Marlene Buch-Pedersen
Yes
Yes; the abstract clearly states its objective, study design, analytic strategy, and lists the main implications and/or significance.
Qualitaitve approach is approriate to address research question; however there is no rationale given and it is clear why researchers chose a qualitative approach as opposed to quantiative or mixed-methods.
Yes; the study has a clear ratione and aim and the approach to inquiry is clear.
Clear on approval and consent. On participant and data protection, researchers clearly state study was approved by "data
No
Yes
No
Design is defensible; choice of method is clearly described and the design is appropriate to the research question being posed. Researchers also gave a clear rationale and justification for data collection and data analysis techniques used. The recruitment process, sampling strategy, and intended participants were outlined in a clear and coherent manner.
Data collection was carried out well; the strategy was clear and the appropriate data was collected to address the research question. The researchers clearly indicated that they were coding the data in a joint effort. The data collection procedure is reliable.
The role of the researchers were clearly described in the recruitment process and analysis, however, it is unclear what their roles were in the interviews apart from designing the questions. Questions that were asked to the participants were clearly outlined,
Context is clearly described; a table is provided of sampled participants and the participant characteristics provided were appropriate in investigating the study's aims.
Methods were reliable; the analytic method chosen investigated the research question posed in the study.
Data is sufficiently rigorous; process of analysis is clear and it is clear how the themes and concepts were derived from the data. The analytic procedure is reliable.
Data is rich; researcher discussed contradictory data and explored different responses in comparing and contrasting between participants. The researchers demonstrated detail and depth well.
Methods were reliable; softwares were not indicated if used but more than 1 reseracher themed and coded transcripts. Researchers used a "joint effort" to analyze the data, impying using a consensus method to resolve differences however it should have been explictly stated.
Findings are convincing; reporting is clear and coherent and findings were clearly presented. The research findings were comptaible with the study design and extracts from the original data were included.
Findings were relevant to the aims of the study; findings were grounded in evidence and adequate captured resposnes most relevant to the study's aims and goals.
Conclusions were somewhat adequate; researchers mostly discussed the findings and made reflections on different responses within the finding, however only two references were made to prior research findings. This seems at odds wit the introduction which states that several factors to help-seeking in psychosis have been identified prior to the study. Some suggestions were made for futher exploration, however, the findings were rich and so it would have made more sense to discuss its clinical implications more as opposed to "individuals with unclear or vague symptoms of

author: Eric Macnaughton, Sam Sheps, Jim Frankish and Dave Irwin
Yes
Yes; the study clearly states its objective, design, analytic strategy, and lists the main implications and/or significance.
Yes; rationale was provided on using a qualitative approach and several examples were given on insight and psychosis and narratives.
Yes; the study had a clear rationale, aim, and approach to inquiry including epistemology.
Clear on reporting on consent and approval; however it is unclear how researchers protected participants identifiable details if at
Somehwat: diagnosis of participant characteristics were provided but it did not state how they were diagnosed (e.g. DSM, ICD
No
No
Design is rigorous; choice of method was clearly presented and the design is appropriate to the researcher question. There were clear accounts of the rationale/justification for data collection and data analysis techniques used and the sampling strategy was theoretically justified. Also, the recruitment process and intended participants were clearly defined.
Data collection was carried out well; data collection strategy was clear and the appropriate data was collected to address the research question. It was not stated how long the procedure took however, the procedure is still reliable as they referenced how previous literature helped design their interview materials, increasing its reliability and replicability. The data collection
The role of the researcher was clearly described; the paper described the researchers role in the recruitment, data collection, and data analysis processes. The paper also described how the research was presented to the participants, including the interview
Context was described to a certain extent; Ethnicity, gender, and diagnnosis was listed however the study only reported the
Methods were reliable; researchers explictly stated a triangulation of methods to improve consistency and reliability.
Data is sufficiently rigorous; process of analysis was clear and it was clear how the themes and concepts were derived from the data. The analytic procedure was reliable.
Data is rich; researcher discussed contradictory data and reflected on them. Responses were also compared and contrasted across participants, inidicating the reseracher's ability to demonstrate depth and detail.
Analysis was reliable; although researchers did not state if softwares were indicated or if analysis was done manually, triangulation was stated to be used and more than 1 reseracher themed and coded the transcripts. Also, the researchers made clear how differences would have been resolved.
Findings are convincing; the reporting is clear, coherent, and findings were clearly presented. The findings were compataible with the study design and extracts from the original data were included.
Findings were relevant to the aims of the study; they were grounded in evidnece and it captured data most relevant to the research question and study aims.
Conclusions were adequate; similarities and differences prior research theories were identified and researchers made clear how findings could be best utilized. Reflections were made on alternative findings by the reseachers, as well. Overall, this enhances

author: Leanne Bogen-Johnston, Richard de Visser, Clara Strauss, Katherine Berry, and Mark Hayward
Yes
Yes; the abstracted stated the aim, design, analytic strategy, and listed its main implications and/or significance.
Yes; a rationale was given for using a mixed-method appropach and the qualitative method was justified. It was clear how prior understandings of hearing voices influenced the current study.
Yes; the study clearly states its rationale, aim, and approach to inquiry.
Clear
Somewhat; concepts of psychosis were highlight but no definition was provided to explain what psychosis is
No
Somewhat; aspects of FEP are defined but no definition is provided
Design is rigorous; choice of method is clearly described and the design is appropriate to address the research question, with clear accounts of the rationale/justification for data collection and data analysis techniques. Also, the sampling strategy, intended participants, and recruitment process was clear.
Data collection was carried out well; strategy was clear, appropriate data was collected to address the research question, the mean and time duration of the data collection was clear and appropriate, and coders were clearly described. Therefore, the data collection procedure was reliable.
The role of the researchers were clearly described in the recruitment, data collection, and data analysis process. It was clear how the research was described to the participants and researcher bias was considered in the analysis.
Context is clearly described; sampled participants are clearly defined and the data of participant characteristics captured were clear and appropriate
Methods were reliable; data was collected more than 1 method and both investigated what they claimed to.
Data is sufficiently rigorous; the process of analysis is clear and it is clear how the themes and concepts were derived from the data. Therefore, the analytic procedure is reliable.
Data is rich; reserachers demonstrated detail and depth in their findings, as well as providing contradictory data and comparing/contrasting across participants.
Analysis was reliable; although softwares used not indicated, more than 1 reseracher themed and coded the transcripts and the study mentioned using a consensus method for resolving differences.
Findings are convincing; reporting is clear, coherent, and findings were clearly presented with extracts from original data included. The research findings were compatible with the study design.
Findings are relevant to the aims of the study; findings were grounded in evidence and data adequately captured forms of diversity most relevant to the reserach question.
Conclusions were adequate; similarities and differences from prior theories and research findings were identified and reflections were made on alternative data. Researchers also amde clear how findings could be best utilized. Overall, this enhances the

author: Ryan Melton, Shannon Blajeski, Diana Glasser
Yes
Yes; abstract states study aims, design, analytic strategy, and lists the main implications and/or significance.
Yes; a rationale is given for using a qualitiatve approach and used examples to clarify how prior reserached influenced the current study.
Yes; the study has a clear aim and the approach to inquiry is clear.
Clear
Yes
Somewhat; pathways to help-seeking is defined
No
Design is rigorous; choice of method was clearly described and the design was apporpriate to the research qusetion. Researchers also clearly described intentended participants and justified their sampling strategy and data collection and analysis. The recruitment process was clear.
Data collection was carried out well; the strategy was clear and appropriate data was collected to address the research question. Also, the mean and duration of time duration of interview materials were listed and coders were clearly described. Therefore, the data collection procedure was reliable.
The role of the reserachers were clearly described in the recruitment, data collection, and data analysis. Reseacher bias considered in the data analysis, however, there was no discussion on how to reduce bias betwee all three interviewers having a
Context was somewhat described. sampled participants and relevant participant characteristics were captured, such as age however no information on ethnicity or gender were listed There was no justification as to why those details were removed from
Methods were reliable; researchers met with the team to compare/contrast notes, which ensured that the methods investigated
Data is sufficiently rigorous; process of analysis is clear and it's clear how the themes an dconcepts were derived from the data. Therefore, the analytic procedure is reliable.
Data is rich; reserachers provided major participant responses as well as minor ones. Althought the reporting was unclear as the comparisons and contrasts were less emphasized as opposed to stating what some participants stated. For example, "theme of
Analysis is reliable; researchers within a team independently reviewed the data and then used a consensus method to resolve any differences.
Findings are convincing; although the reporting is not clearly presented, extracts from the original data were included and the findings are convincing and they are comptaible with with the design.
Findings were relevant to the aims of the study; findings were grounded in evidence and responses captured the most relevant information to the study aims.
Conclusions were adequate; similarities and differences from prior and research findings were identified and reseracher discussed the major and minor findings. Researchers also made it clear how the findings can be best utilized in the future. Overall, this enhances the understanding of the research topic

author: Abigail M. Judge, Sue E. Estroff, Diana O. Perkins, David L. Penn
Yes
Somewhat; lists objective, results, and main implications, however study design is vague and it is unclear what "qualtiative methods were used" and how.
Yes; a rationale is given for using qualitative approach. Researchers made it clear that it was the lack of information on help-seeking processes in psychosis in the US that influenced their research.
Somewhat; the study has a clear rationale and aim but approach to inquiry is vague and it is unclear what the aim of the study is until we reach data collection apart from "using qualitative methods"
Clear on ethical approval and consent process; unclear on how identificable details of participants were changed if it all and how
Yes
Yes
No
Design is somehwat rigorous; Choice of methods were left vague up until the data collection procedure. Method was described in more detail in the data collection procedure and justification for methods chosen were provided. Intended participants were not defined and eligibility was stated to be established when discussing sampled participants. It is unclear what participant
Data collection strategy was somewhat clear; Appropriate data was collected to address the research question and they reported how long the study interviews took in total. However, it is unclear who the "raters" were in the stage 1 and if the researchers themsleves were the interviewers. Therefore, the data collection procedure is not that reliable.
The role of the researchers are clear in the analysis but not data collection and recruitment. The paper does detail what questions participants were asked but it was unclear who was intervieiwing them. There also was no mention of researcher bias
Context was described; sampled participants were clearly defined and data on participant characteristics and demographics were clear and appropriate
Methods were reliable; researchers compared and contrasted responses and the methods investigated what they claimed to.
Data is sufficiently rigorous; the process of analysis was clear and it was clear how themes and concepts were derived from the data. Therefore, the analytic procedure is reliable.
Data is rich; reseracher discussed contradictory data and demonstrated detail and depth well. Researchers also compared and contrasted responses.
Methods were reliable; using grounded theory they constantly compared responses between researchers. Researchers also noted how the resolved any differerences.
The analysis was convincing; it was the first study in the US on this topic, so it may have lacked details in some areas but the reporting was clear and coherent and findings were clearly presented with extracts from original data included. The research findings were compatible with the study design.
Findings were relevant to the aims of the study; findings were grounded in evidence and the data that was captured was relevant to the study aims and approach to inquiry.
Conclusions were adequate; with the few studies prior to this one, researchers were able to find similarities and differences from prior reserach findings that were available at the time. They also reported in caution with clinical implications due to the limitations. Reflefctions were made on the findings as well. Overall, this enhances the understanding of the research topic.

Appendix E. Full table of data extraction for themes

Source	**Spikol & Murphy (2019)**	**Singh et al. (2013)**	**Jansen et al. (2015)**	**Bay et al. (2016)**	**Ferrari et al. (2018)**
Category/Concept	Theme: Age of onset (?)	Theme: The importance of family in help-seeking	Theme: Stigma and fear of the psychiatric system as barriers to help seeking	Theme: Failure to recognize symptoms of psychosis	Theme: Women’ s barriers to EI services: the role of female stereotypes
Category/Concept	Theme: respondent distress was associated with psychosis onset timeframe	Theme: Ethnic differences in the appraisal of low-level (non-psychotic) psychological distress	Theme: The impact of traumatic experiences on the experience and development of psychosis	Theme: Difficulties expressing their experiences	Subtheme: Feeling ignored and mistrusted
Category/Concept	Theme: negative-voice auditory hallucinations	Theme: Religion and culture as frameworks for help-seeking decisions	Theme: The importance of significant others	Theme: Concerns about stigma	Subtheme: Being labelled as ‘ overdramatic’ or a “ drama queen"
Category/Concept	Theme: visual hallucinations	Theme: Crisis point as an important variable in help-seeking	Theme: The experience of safety and trusting the early detection team	Theme: Poor psychosis detection skills among health-care professionals	Subtheme: Being ‘ too functional’
Category/Concept	Theme: Paranoid delusions	Theme: Ambivalence: competing and contrasting explanatory models		Theme: Lack of awareness or understanding of TIPS and TIPS Information-	Theme: Men’ s barriers to EI services: Therole of male stereotypes
Category/Concept	Theme: Insight	Theme: Stressful life events as attributions, which prevent medical help-seeking	Theme: The relief of receiving a diagnosis		Subtheme: The need to be strong and in control
Category/Concept	Subtheme (?): Minor symptoms	Theme: Ethnic differences in personal and family coping			Subtheme: The need to be in control
Category/Concept		Theme: Mistrust/suspicion of services			Subtheme: Physicality and differences inresponses between gender
Category/Concept					

Nordgaard et al. (2020)	**Cabassa et al. (2018)**	**Kamens et al. (2018)**	**Jansen et al. (2014)**	**Tanskanen et al. (2011)**	**Hardy et al. (2020)**
RQ1- Theme: Step 1. Recognition and identification of the problem	Theme: Client/family factors - Attribution of symptoms	Theme: Life pre-duration of untreated psychosis - Daily life as unremarkable	Theme: Facilitating help-seeking - Support from significant others in initiating helpseeking process	Theme: Understandings of symptoms and experiences - attributions of symptoms	Theme: Perceptions of stigma
RQ1 - Subtheme: Involving others in identifying the problem	Theme: Client/family factors - Self-reliance	Theme: Life pre-duration of untreated psychosis - Existential concerns about life as a young adul	Theme: Facilitating help-seeking - Internet as a source of information of psychosis and	Theme: Understandings of symptoms and experiences- Response to symptoms	Subtheme: Shame and fear
RQ1 - Theme: Step 2. Deciding to act Social problems	Theme: Client/family factors - Stigma	Theme: Life pre-duration of untreated psychosis - For some, struggles started early	Theme: Barriers to help-seeking - Fear of stigma and self-stigma	Theme: Help-seeking processes	Theme: Outcomes associated with stigma
RQ1 - Subtheme: Physical problems	Theme: Client/family factors - Cloud of uncertainty	Theme: The onset of challenges - Implicit conceptualizations of onset	Theme: Barriers to help-seeking - Symptoms viewed as normal or lack	Subtheme: Unawareness of problems	Subtheme: criminalization
RQ1 - Theme: Step 3. Selection of source of help Involving the authorities	Theme: Healthcare factors - Interpersonal connections	Theme: The onset of challenges - Meanings of DUP within TSD		Subtheme: Attribution of problems to mental illness	Subtheme: isolation and/or alienation
RQ1 - Subtheme: Physical Problems	Theme: Healthcare factors - Quality of care	Theme: The onset of challenges - Negative Pathways to Care		Subtheme: Other attributions of problems	Subtheme: relationship between stigma and treatment interfering behaviors
RQ1 - Theme: Step 4. Making contact Worrying about seeking help	Theme: Healthcare factors - Family involvement	Theme: Experiences during TSD and DUP - obstacles to independence		Theme: Beliefs and knowledge about mental health services - Stigma	
RQ1 - Theme : Step 5. Disclosure - others not reacting	Theme: Healthcare factors - Care transitions	Theme: Experiences during TSD and DUP - Feeling distant and different from others		Theme: Beliefs and knowledge about mental health services - lack of knowledge	
RQ2 - Theme: Insight into illness		Theme: Experiences during TSD and DUP - Spiritual–existential and social justice concerns		Theme: Responses of social networks to illness onset and helpseeking - Responses of immediate social networks	

Judge et al. (2008)	**Melton et al. (2020)**	**Bogen-Johnston et al. (2019)**	**Macnaughton et al. (2015)**
Theme: Recognizing changes - "It was normal"	Theme: Core Categories - Recognition of Symptoms and Presence or Absence of Supportive Others	Theme: Effect of disclosure on the self	Theme: Becoming demoralized
Theme: Recognizing changes - "explanatory	Theme: Signs and symptoms	Subtheme: What problem?	Theme: Experiencing an impact
Theme: Responding to changes -	Subtheme: Hallucinations-Only Facilitated Recognition	Subtheme: I feel too ashamed	Theme: Finding a fit
Theme: Responding	Subtheme: Presence of Delusions Complicated	Subtheme: Reaching desperation	Theme: Envisioning illness in the background of life
Theme: Coming to terms with	Theme/Subtheme: Physical Deterioration Prompts Action by Family	Theme: Effect of disclosure on others	
	Theme: Arrest Facilitates Action	Subtheme: Concerns about others	
		Subtheme: How will they respond?	
		Theme: Help-seeking	

Appendix F. Full table of list of ideas, metaphors, juxtapositions, etc. for each theme and study. *Key: Red font = comments/reflections from the author of this meta-ethnography; green font= participant quotes; blue font= comments/reflections from the authors of this study*

Source	
Category/Concept	
Category/Concept	
Category/Concept	
Category/Concept	
Category/Concept	
Category/Concept	
Category/Concept	
Category/Concept	
Category/Concept	

Spikol & Murphy (2019)
Theme: Age of onset (?) Note: not sure what to report because it is very unclear if these are results from the IPA or the authors attempt of quantiative analysis
Theme: Auditory Hallucinations: "Hearing my dead best friend screaming for help from Hell" Auditory hallucations were most prevalent, with 56.7% reported either hearing voices, noises, or "things that weren't there." The
Subtheme: Voice personification and characteristics Voice identity was categorized into 3 groups: unknown voices, friends/family, and God, Satan, or angels/demons; Most participants described voices as being "in their heads" but early childhood commenters also described voices coming from "under the bed." Voice hallucinations over live conversations or television also occured (note: unclear how common this particulary experience was)
Theme: Visual hallucinations: “ Faces started appearing in my windows.” 40% reported visual hallucinations; 6.7% saw "shadow people," but also participants reported seeing normal or abnormal phenomena, ranging from people walking down the street and animals to shadows, orbs/lights, frightening/disgusting visions, and patterns/textures in motion (Note: unclear how common these characteristics were as researchers did not note them and the study they provide did not come with tables listed). Frightening visions included: demons, humans/animal corpses, supernatural
Theme: Paranoia: “ There is always someone watching.” 30% reported paranoid ideation; common theme was being the victim of the attentions of authority figures, including parents,
Theme: Delusions: “ Hidden messages pertaining to me specifically.” 30% experienced delusions covalent with paranoia; 7.3% reported religious delusions and 8% believed they received a special message or pattern to decode. Most described the delusional state as unpleasant with language use comparable to describing dreams/nightmares (Note: unclear if this how participants compared it to dreams/nightmares).
Theme/Subtheme (?): Minor symptoms Note: Authors did not make it clear how they categorized "minor symptoms"
Theme/Subtheme (?): Insight Note: Authors did not make it clear how they categorized "Insight" Majority of sample discussed gaining insight in reference to experiences. 43% cited self-realization that their experiences "weren't right"; 18.7% reported retrospective insight; 16.7% reported that another person helped them gain insight; 19.3 did not

Singh et al. (2013)
Theme: The importance of family in help-seekingthere were ethnic differences with regard to which family member intervened and the types of familial networks they tapped into for finding help; most white respondents sought help in consultation with members from the nuclear family and did not seek help from religious or cultural sources; black and Asian participants said help was sought in consultation with larger family networks (aunts, uncles, grandparents, cousins); almost all British Pakistanis
Theme: Ethnic differences in the appraisal of low-level (non-psychotic) psychological distressThere were ethnic differences in how psychological distress was conceptualized; majority of white parents recognised the early signs of psychological dysfunction as a ‘ serious problem’ that required medical intervention; ethnic minority carers tended to normalize symptoms,
Theme: Religion and culture as frameworks for help-seeking decisionsPakistani service users often had multiple attributions; help was sought from the agency thought to be most appropriate for a particular attribution. For example, a young Pakistani man failed to seek medical help because he had a religious framework that both confirmed his symptom as spiritual in origin and legitimised the use of spiritual intervention: "In the first place the reason why I got it was because I thought there was an evil spirit around me, because every time I used to wake up in the night, I used to feel as if there was something pressing down on me
Theme: Stressful life events as attributions, which prevent medical help-seekingPsychological distress was contexualized to stressful life events across all ethnic groups' narratives, as stressful life events preceded or emerged alongside symptoms, making it difficult for carers to differentiate illness from reaction"He had struggled with diabetes, was not doing well at school, his friends had left the neighbourhood, the band he used to play for no longer met. Our marriage had broken, I just thought he is a young lad and is not very happy. He also smoked cannabis and I knew all along that was doing him the utmost damage"
Theme: Ethnic differences in personal and family copingAcross all ethnic groups' narratives, families made significant changes in help-seeking for the service user, e.g. moving out of the family home to live with the user to monitor his mental state and provide care (a white mother); ensuring that the user had personal space and asking family members to make accommodation for
Theme: Crisis point as an important variable in help-seekingEthnic differences were observed in the ways in which crises unfolded and were dealt with, relating to illness attribution; white families with a biomedical attribution were able to find help through their GPs or NHS, but some of them only received help after a crisis. Note: in demonstrating ethnic differences in crisis points, authors used these two examples below1) A young black Caribbean man, had been hearing voices. He followed his mother to his uncle’ s house and was told by his mother to go back home. While on his way home he saw a police vehicle and asked the police to drop him home as he was hearing voices and was distressed. When they did not take him seriously he got angry and hit a policeman, ending up in services through the criminal justice system. 2) A young British Asian man came to
Theme: Ambivalence: competing and contrasting explanatory modelsEven in the cases involving a religious framework to make sense of the distress and coping, service users' narratives were seen as ambivalent as they constantly searched for explanations for their experiences."My parents gave me a taweez [amulet], but I did not believe that it could take things away""And that could
Objective 2: to explore ethnic differences in stigma, mistrust or suspicion of services (Note: No header theme provided)Carers from ethnic minority backgrounds were dissatisfied with services more often than white carers, even though white carers had similar difficulties as non-white carers in accessing cares; with Asian carers, the dissatisfaction was partly related to anxiety about not knowing what was causing the illness and also to worries about not getting the right care. "Every time I took her to the GP (every 2–3 weeks) they told me nothing was wrong but I told her I can see changes in her; she is losing weight, she looks
Mixed-method study at BSMHFT; Thematic analysis on 132 participants.

Jansen et al. (2015)
Theme: Stigma and fear of the psychiatric system as barriers to help seeking8 participants expressed fear of psychiatric institutions and horror-like visions of hospital admission as barriers to help-seeking."I had already seen lots of horror-movies, and read a lot of crime novels and horror-novels, and had seen something about a haunted psychiatric hospital in the US""I think I still had Breivik in my head, you know, and the guy is nuts, and then I' m sitting there thinking, ' shit, I don' t want to be in
Theme: The impact of traumatic experiences on the experience and development of psychosisParticipants (Note: authors did not note how many) reported experiences of adverse events, such as emotional neglect, sexual abuse, and bullying. 7 participants reported serious traumatic events; for some, these experiences represented the most troublesome psychological material, which
Theme: The importance of significant othersAll 10 participants described how significant others, mostly their parents, helped in finding appropriate treatment. "They' ve just been there the whole time, they don' t really have to do much, they' ve just been there."Many of the participants did not tell their parents about their most distressing symptoms as they felt guilty for upsetting them and wanted to protect them."I experienced a lot of guilt and I was worried about making it worse (mother' s stress and depression)." The majority of service users had the experience that their family members were adequately informed and involved in treatment, although the level of needs varied a lot between families
Theme: The experience of safety and trusting the early detection team9 participants stated having a good alliance with the early detection team, describing it as friendly, non-threatning atmosphere, and the positive experience of being asked a number of specific questions to help them tell their story - often for the very first time. "They were listening and came up with suggestions, because I' m having difficulties opening up, so they were fishing in the right way. They were calm and took all the time needed." "It was very calm and down to earth, it was very nice actually . . . you could sit back and just feel relaxed, in spite of being nervous."
Theme: The relief of receiving a diagnosisAll of the participants described receiving a diagnosis as a somewhat positive experience. It was a relief to get the opportunity to talk about their difficulties, to find out that someone could understand their anomalous experiences and finally to see the prospect of getting adequate treatment."I thought it was great to receive a
In-depth interviews were conducted with 10 service users who were diagnosed with a first-episode non-affective psychosis and who were seen by an early detection team (TOP) and currently enrolled in a specialized early intervention service for this disorder (OPUS). Their interviews were analyzed via thematic analysis.

Bay et al. (2016)
Theme: Failure to recognize symptoms of psychosisMajority of participants reported failing to understand they needed help during onset, but instead believed symptoms and changes would disappear on their own without intervention. One participant thought it might be a normal experience of adolescence. Many participants reported that family and friends noticed symptoms and changes in mood and behavior first; family or friends attributes these changes to difficulties in concentration, teenage
Theme: Difficulties expressing their experiencesAn additional obstacle to seeking treatment was uncertainty about how to ask for help. Many participants had trouble explaining their symptoms to healthcare staff. When they first entered psychiatric treatment, healthcare professionals initially misinterpreted symptoms as depression and anxiety. One participant reported that
Theme: Concerns about stigmaMany participants reported that they deliberately hid their symptoms due to concerns about the reactions of others. "I was a teenager and my parents would be informed [that I was receiving help from the health service]. And I was not ready for that. I did not want them to know or become concerned or to start worrying for me."Note: unclear if these concerns were for many, but not all, or if stigma was a concern for most service users?
Theme: Poor psychosis detection skills among healthcare professionalsMore than half of the participants reported that healthcare professionals failed to recognize symptoms as psychosis. 1 participant raised concerns about his symptoms with his GP over a 1 year period until it went correctly identified. "I tried to explain the problems I felt were developing at my workplace. I believed that my colleagues were manipulating me and creatingproblems for me (. . .). Finally, the doctor assessed my concerns as a part of psychotic delusions andI was admitted to my first hospital stay."Some participants had sought help repeatedly from their GPs or the school nurse during periods when they experienced troubling symptoms. At times, they received treatment from GPs,
Theme: Lack of awareness or understanding of ‘ Treatment and Intervention in Psychosis Study' (TIPS) and TIPS Information campaigns (ICs)Majority of participants said they've seen TIPS in newspapers and posters in schools. 2 participants reported having not seen the ads nor had heard about TIPS via other outlets. 1 participant reported noticing the ads more frequently when
8 TIPS-2 patients wit hduration of untreated psychosis lasting for more than 6 months were interviewed. The interviews were analyzed using a meaning condensation procedure.

Ferrari et al. (2018)
Theme: Women' s barriers to EI services - the role of female stereotypesWomen who took part in the focus groups and in-depth interviews described an active role in seeking help for psychosis. Women reported how these experiences influenced their willingness to share openly their symptoms and seek professional help.A woman who took part in the interview described how, after many attempts and rejections, she started to doubt herself."It was hard though [to keep looking for help after many
Subtheme: Feeling ignored and mistrusted Women felt that family members and health-care providers often dismissed their calls for help, as they perceived it as an attempt to gain attention. Women reported their symptoms were underestimated by healthcare providers and/or denied. People described feeling ignored and/or mistrusted in their requests for help. "I heard someone mention
Subtheme: Being labelled as "overdramatic" or a "drama queen"Women described how family members' and/or health care providers gender' stereotype impacted their overall trust in the system. They reported being labelled as "overdramatic" or "drama queen.""I' ve been labelled as a drama queen actually,by my mom, by EVERYONE, because sometimes I do get a little overdramatic.… But because I' ve been labelled as that, when I go to hospitals, they don' t really treat me right away. They just think it' s the one main thing, and then just—because I' ve been labelled as that.
Subtheme: Being "too functional"Women recounted how being identified as ' too functional' by healthcare providers became a barrier to timely access to EI services. They recognized that this term came from the medical language to which they had been exposed and described it as a person' s ability to cope with psychotic symptoms and carry on with their everyday life. "It doesn' t make sense. I know my diagnosis, (…)you can' t tell me what I do not have because I' m highly functioning—that' s what my doctors aid, " you' re highly functioning there is no way you' re schizophrenic, you don' t have the symptoms,you don' t look like it, you don' t appear it."Functionality, as a theme, was only present in women' s focus groups and
Theme: Men' s barriers to EI services- the role of male stereotypesMen who took part in the focus groups also described how gender stereotypes played a role in disclosing early psychosis symptoms to family members and friends.
Subtheme: The need to be strong and in controlMen described how male stereotypes, such as men being strong, in control, and unable to look weak or vulnerable, stopped them from disclosing psychotic symptoms and asking for help (Note: not clear if all males attributed this to stereotypes or only some of them, or if these are the authors' interpretations). "I think that, um … being a guy, that matters,' cause I come from a culture that, that um, tells the guy to be more hardworking, so if you complain about, like voices, people tend to think, 'oh, you arejust busy,' that' s why, you know, you have to do well in school. For me, my culture, men are supposed to really do well than girls. Where men are supposed tobe more strength, the more that are, uh more …workers and hardworking."Some men talked about turning to drugs as a way to cope with psychotic symptoms and keep
Subtheme: Physicality and differences inresponses between genderMen also described how being a man and their physicality may have influenced the kind of responses they encountered during their psychotic episodes. For example, men described been often restrained by police because of their robust body structure during a psychotic episode."May I just say … I mean, some
A qualitative approach was used to examine gender differences in the routes to care. 4 focus groups and four individual in-depth interviews with 25 serviceusers of early intervention services from African-origin, Caribbean-origin and European-origin populations were conducted. A thematica analysis was used on the transcripts.

Hardy et al. (2020)
Theme: Perceptions of StigmaStigma ws experienced as negative by individual and family.
Subtheme: Shame and fear "My family kept quiet about what was happening to my sibling. I was a teen just starting college, and I recall my parents asking me not to say anything to friends or family. It was something they were ashamed of and my parents believed it to be their fault.” Participants also expressed the fear associated with public stigma “ My son was afraid if he was
Theme: Outcomes associated with stigmaResponses that indicated concern for and actual perceived consequences linked to the impact of stigma.Not all respondents identified with stigma as a factor that influenced their help-seeking.“ Family and friends were very supportive; we are proactive and readily seek medical & psychological services. For us, stigma did not play a large role; misdiagnosis & mistreatment was the cause of delay.” Notably, the role stigma played on the misdiagnosis and mistreatment (i.e. lack of education, resources) is unknown.1 participant remarked on how their fear was a result of stigmatizing perceptions of mental illness within the the family llustrating the link between perception of stigma and outcomes relating to
Subtheme: Criminalization"The court system criminalized his obvious psychotic behavior”
Subtheme: Isolation and/or alienation“ My brother was ashamed of what was happening to him and didn’ t want his peers to know, so he didn’ t reach out for interpersonal support. That pattern has continued to this day, and he has become somewhat isolated and lonely which hurts his self-esteem” His friends dropped having contact with him."
Subtheme: The relationship between stigma and treatment-interfering behaviors E.g. treatment rejection, medication non-compliance, delay in treatment, and substance abuse 1 participant noted that they “ Didn’ t trust medical health care providers enough to disclose [their] symptoms because [they] feared being involuntarily committed or treated . . . ” A family member identified that stigma had resulted in their loved one not adhering to their medication regimen: “ My family member would not go to a mental health clinic for counseling. He accepted home visits of the drop in type. He [was not] willing take medication.”

Tanskanen et al. (2011)
Theme: Understandings of symptoms and experiences - attributions of symptomsMajority of service user participants (n=18) described a period in which they did not understand their experiences as a mental health problem or something that is worth seeking help from health services. “ I just thought they [symptoms] were normal, I thought everyone got them. Obviously everyone didn’ t get them.” Carers (n=6) also described similar difficulties in recognizing symptoms as signs of psychosis,
Theme: Understandings of symptoms and experiences- Response to symptomsAlmost half the service users (n=10) described that they thought symptoms were transient and would resolve on their own without the need for further intervention. One-third of carers thought the same way. These accounts seemed to be linked to longer duration of untreated psychosis and attribution of
Theme: Help-seeking processesService users and carers describe change over time and ambivalence in their response to difficulties.
Subtheme: Unawareness of problems11 respondents (Note: I'm assuming these are only service users?) describe remaining unaware of their symptoms of psychosis until they made contact with mental health services. Help-seeking for these individuals was therefore often complicated, prolonged and involved various attempts to intervene by family and friends, community organizations, statutory and emergency services. In some cases, help-seeking was initiated without service users’ knowledge and/or consent.“ I went to get a sick note from the GP and I explained some of the experiences that I’ d had, which for me was of no concern at all, it was perfectly normal a lot of the things that had happened, but I needed time to kind of you know process
Subtheme: Attribution of problems to mental illness6 service users reported gradually acknowledging that their problems were mental health-related and thus began help-seeking. These respondents appeared to recognise a need for help as their symptoms became unmanageable and culminated in crisis. Consistent encouragement and pressure from others to seek help aided help-
Subtheme: Other attributions of problemsThe remaining 4 service users acknowledged a need for help but did not view their difficulties as mental health problems, so instigated more general help-seeking.“ I thought okay there is something wrong with me. Then I kept phoning the ambulance because I thought I was having a heart attack and it was really weird.” All carers came to recognize a need for help although the time-frame for help-seeking varied considerably. Carers noticed uncharacteristic and bizarre behaviours which alerted them to consider taking action, although a majority (n = 5) reported that help-seeking was not initiated until a crisis point was reached.“ [...] My house was full of relatives so I wasn’ t completely focused on her but I was noticing she was behaving oddly, she was kind of disengaged. She was saying odd things, she was talking inappropriately to the
Theme: Beliefs and knowledge about mental health services - StigmaMost service users (n=15) described concerns about stigma as a barrier to help-seeking.Fear of negative reactions to mental illness (n=12); fears about mental health services (n=5); fears about social consequnces of getting involved with metnal health services (n=5).“ They were like ‘ go to the doctors and tell
Theme: Beliefs and knowledge about mental health services - lack of knowledgeIdentifying an appropriate service and route to treatment had been difficult for both service users and carers. Over half of service users (n = 12) talked about not having adequate knowledge about mental health services and the types of help available at illness onset. 6 reported thinking that help did not exist for the psychotic symptoms they were experiencing.“ I didn’ t even know that the services existed for these problems. I really was totally oblivious to mental health.” Similarly, most carers (n = 6) reported having insufficient knowledge
Theme: Responses of social networks to illness onset and helpseeking - Responses of immediate social networksMost service users (n = 19) reported being encouraged to seek help by their immediate social networks (friends, family members and partners), but 9 had also experienced unhelpful responses ranging from not recognizing or minimising the severity of illness to alarming or critical responses. One third of carers also described unhelpful responses from others in their social network when
Theme: Responses of social networks to illness onset and helpseeking - Responses of community organisationsPrior to first

Jansen et al. (2014)
Theme: Facilitating help-seeking - Support from significant others in initiating helpseeking process10 participants made reference to significant others being crucial in the process of disclosing symptoms, acknowledging the severity of their problems and motivating them to seek help; Significant others often pointed out change in behaviours that the service usersthemselves were unaware of."… if I didn’ t have my parents who noticed that my psychosis was developing, I wouldn’ t have admitted I
Theme: Facilitating help-seeking - Internet as a source of information of psychosis and treatment services4 participants reported the use of the internet as a first attempt to access knowledge about their psychosis symptoms. "… well, I had just looked up the psychiatric emergency ward on the Internet … and I just went up there since I was in the area.""… It was really scary to find out
Theme: Barriers to help-seeking - Symptoms viewed as normal or lack of knowledge about mental illness9 participants described a lack of knowledge about mental illness, symptoms of psychosis or normalisation of the experiences as barriers to help-seeking."… I didn’ t know what was wrong with me, because I didn’ t know anything about it, at all … I think the reason that I didn’ t tell many people about it, really was because I didn’ t know what it was myself. I mean, at that time I could say I had some thoughts in my head telling me that I had done some things; I mean it was really difficult, when you didn’ t know what it was."" … I think I kept it to myself because I thought it was normal."" … I just thought ‘ it’ s just that depression
Theme: Barriers to help-seeking - Fear of Stigmatisation6 participants talked about shame and fear of stigma in relation to mental illness and how this made them less inclined to disclose symptoms and seek appropriate treatment.However, when they eventually did talk about their difficulties with other people, they generally referred to this as a positive experience (Note: does this refer to only the 6 participants that expressed hestitation towards seeking help or all participants)"It’ s a bit of a taboo being ill.""… it was just a kind of private thing … I thought it was embarrassing.""… I thought I should talk with someone about it … I just felt it was completely ridiculous to … you’ re beginning to hear voices and feel someone’ s after you when there’ s no

Kamens et al. (2018)
Theme: Life pre-duration of untreated psychosis - Daily life as unremarkableParticipants used phrases such as “ kind of mundane” , “ pretty chill” and “ nothing special” , to describe their daily lives and routines prior to the onset of challenges. Participants also reported engaging in social and leisure activities, school and/or work. These “ mundane” daily experiences were sometimes described as positive (e.g. “ my life was good”) and sometimes as unsatisfactory (e.g. “ I was not super happy
Theme: Life pre-duration of untreated psychosis - Existential concerns about life as a young adultPre-DUP experiences were often characterized by existential concerns about life in general and young adulthood in particular. Participants frequently worried about their educational, vocational, financial and/or relational futures. “ How am I gonna escape just like continuing to
Theme: Life pre-duration of untreated psychosis - For some, struggles started early5/10 participants reported struggles that began in adulthood; half of the participants described challenges during childhood and/or adolescence. Some participants used clinical terms to describe early difficulties. “ I wanted treatment for anxiety . . . [It started] when I was like a teenager” . Some participants reported difficult events such as significant interpersonal losses during their earlier years.
Theme: The onset of challenges - Implicit conceptualizations of onsetParticipants described the TSD as comprising one or more overwhelming challenge(s) that disrupted previously mundane daily lives (Note: unclear just how many participants reported this) Examples included challenges in work, school, legal situation, lifestyle and/or relationships. “ Doing far, far too much” to keep up with his busy academic and extracurricular schedule. There were no clear qualitative differences between experiences of TSD in participants within their first two months of EIS treatment and those receiving services for one year or more.All participants described a TSD characterized by substantial changes, loss or other difficulties in their interpersonal lives. Examples
Theme: The onset of challenges - Meanings of DUP within TSD (trajectory of subjective difficulties)For all participants, the onset of psychotic experiences (i.e. the onset of DUP) was meaningfully contextualized by the TSD. In some cases, psychosis was described as one in a series of life challenges.“ My grandfather passed away . . . and then that’ s when the thoughts [that
Theme: The onset of challenges - Negative Pathways to CareAll participants reported 1 or more PtC that were experienced as distressing, including encounters with the police, jail or prison; mobile crisis or ambulance services; emergency departments (ED) or observation units; and hospitalization. Participants depicted negative PtCs as particularly unsettling; 1 participant described emergency departments as "crazy", "terrifying", and "spiritual hell"; another stated that the emergency department staff "Just sat me down and kinda broke my heart. Cuz they made me wait for hours” .Negative PtCs extended the duration of TSD, as distressing contacts with law enforcement, emergency-medical and/or psychiatric services were experienced as a continuation of difficult life events. As a result, initial contact with treatment often constituted the end of DUP but not TSD. For
Theme: Experiences during TSD and DUP - obstacles to independenceDuring TSD and DUP, participants strove towards, but struggled to achieve independence.Financial hardships were particularly common. “ Although I was successful . . .as far as not milking my parents for . . . funds, I wasn’ t self-sufficient in the truest sense” . Several participants described over-exerting
Theme: Experiences during TSD and DUP - Feeling distant and different from othersFor all participants, the TSD and DUP were characterized by feelings of distressing interpersonal distance, isolation, distrust and/or alienation. Some participants reported having limited social support (e.g. “ I was the only one that knew I was going through . . . I was very alone”), others reported feeling alienated despite social support that they experienced as insufficient (“ My mom, she helped me. She was more my big supporter . . . cuz I don’ t have nobody”).Feelings of interpersonal alienation sometimes coincided with feeling different from
Theme: Experiences during TSD and DUP - Spiritual–existential and social justice concernsFor some participants TSD was characterized by spiritual–existential and/or social justice concerns. “ I was just thinking about life in general and like trying to answer all of life’ s questions” . "[W]e moved to an inner-city school where it was predominantly Black and I saw people who looked like me, who were genuinely struggling with the same material . . . that could’ ve been me. So I kind of just had to get
Theme: Perceptions of support8/10 participants reported a period of time prior receiving mental healthcare that they would have

Cabassa et al. (2018)
Theme: Client/family factors - Attribution of symptomsMajority of families and participants (75%) reported experiencing misattribution or uncertain attribution of symptoms; this included attributing symptoms to drug use, uncertainty about what the cause was not knowing something was not right, not thinking symptoms were related to a mental illness, were a part of "teenage issues" or did not feel the symptoms were "going to become that big."These attribution struggles seemed to be more common
Theme: Client/family factors - Self-reliance45% of the sample described a tendency towards self-reliance in coping with psychosis symptoms.Self-reliance was defined as not telling anyone what was happening and trying to solve porblems on their own. This was often driven by uncertainty about what they were experiencing, hopelessness that others could help, distrust of
Theme: Client/family factiors - Stigma60% of participants reported stigma towards mental illness and treatments played an important role in help-seeking decisions and delays in care .Fears and misapprehensions about psychiatric treatments negatively impacted participants’ and family members’ decisions to seek and remain in mental health care. Some participants talked about how family members expressed disapproval of needing or taking psychiatric medications, which caused ambiguity as to whether the participant should adhere to doctor’ s recommendations. Stigma also impacted delays in care through label avoidance as some participants refused to take medications to avoid being labeled as mentally ill.Note: no quotes provided
Theme: Client/family factors - Cloud of uncertaintyThe factors above formed a cloud of uncertainty shaping interpretations and decisions to seek and remain in care. This uncertainty clouded two aspects of the help-seeking process: a) initial decisions to seek professional careb) ongoing decisions to remain in mental health care until entry into RAISE Connection. Lack of knowledge and awareness about the symptoms, causes, and severity of psychosis, contributed to this uncertainty by impacting initial symptom recognition, and exacerbated the ambivalence surrounding how participants and family members made sense of and reacted to psychosis. The nature of psychosis, especially if it was a gradual onset that was not overtly noticed by others and
Theme: Healthcare factors - Interpersonal connections90% participants reported that interpersonal connections participants and family members made with providers impacted pathways to care.Positive connections led to treatment engagement by enhancing trust and reassurance, providing emotional/informational support, and encouraging open communication and shared-decision.
Theme: Healthcare factors - Quality of care95% participants discussed perceived quality of mental health care that shaped pathways to care.High quality of care was described as getting accurate diagnostic information, positive experiences in which participants and family members were involved treatment decisions, alleviating participants’ symptoms and restoring functioning.High quality of care resulted in engaging participants in treatments before entering EIS. Examples of low quality included episodes in which participants and family members did not receive clear information about treatment options and side effects or not getting any mental health care or referrals from providers. Low quality of care included being treated poorly, not receiving appropriate evaluations and medications, and feeling trapped and traumatized by these experiences.Note: No quotes
Theme: Healthcare factors - Family involvementThe manner in which family members were involved in participants’ treatment was an important factor in the pathways to care and was mentioned by 80% of participants. Positive family involvement included providers informing them about participants’ progress and treatment decisions. Negative involvement resulted in
Theme: Healthcare factors - Care transitionsThe transitions between settings particularly from inpatient to outpatient care, impacted connections to treatment and was discussed by all participants.Across all settings (e.g., schools, outpatient clinics), coordinated transitions were instances in which participants experienced positive services and referrals that facilitates their connections to mental health treatments in their pathway to care.Fragmented transitions were characterized as not receiving care coordination support and having unclear options for follow-up care.Note: No quotes provided

Nordgaard et al. (2020)
RQ1- Theme: Step 1. Recognition and identification of the problemAll participants recognized they had some kind of problem and needed help to solve it but none of them clearly identified their psychotic or otherwise anamolous experiences as symptoms of a mental disorder, and most of them did not seriously question the reality status of these experiences. For example, patient 1 seemed especially unconcerned about this; patient 1 described how hwe had problems with his neighbors for almost a year. They
RQ1 - Subtheme: Involving others in identifying the problemBy contrast, the rest of the patients did consider the possibility that some of their problems could perhaps be signs of an illness, maybe of mental character. Patient 7 had doubts about how to interpret her troubels sleeping due to voices screaming in her head. she involved a friend in the process of identifying the
RQ1 - Theme: Step 2. Deciding to act - Social problemsAll participants reported experiencing symptoms of psychosis for months or years before seeking help.Common for most of them was that the reason they decided to act now was that their social situation had worsened considerably.Patient 1 could not stay in his apartment because of trouble with his neighbours and he had problems at work as well.“ Things became so bad. I started to shake and felt really bad. At work I didn’ t want to serve the customers and I would hide in the backroom of the shop. I avoided contact with other people.” Patient 6 was about to start a new education and feared that she could not handle the studies because of her problems, while Patient 7 was afraid that she might lose
RQ1 - Subtheme: Physical problems2 participants described worries regarding their physical health that led them to seek help.“ My heart was racing and I had never felt so anxious before.” To many of the patients the support of family or friends played a crucial role in deciding to act. Patient 9, e.g., went to see the school counsellor at the behest of her boyfriend and stated that had it not been for his insistence, she would probably have preferred suicide over seeking psychological help.
RQ1 - Theme: Step 3. Selection of source of help Involving the authoritiesThe selection of source of help seemed to logically follow the patients’ identification of the nature of their problem. However, a few of the patients had difficulties in figuring out the details of their problem, and this led to difficulties in selecting a source of help. For example, Patient 1, who had identified
RQ1 - Subtheme: Urgent need for helpFor Patient 2, who was convinced that she was being kept under surveillance but did not know by whom or for what exact purpose, it was not clear where to seek help. Thus, she asked her neighbours, colleagues, and even an accountant for help before finally calling her general practitioner, who suggested her to go the psychiatric emergency room. Yet, this did not lead her to think that her experiences could be symptoms of a mental disorder, but her need for help was urgent. “ I didn’ t know what else to do. And at this point I felt that nothing mattered anymore” .Patient 3 was already in psychiatric treatment for a non-psychotic disorder. She tried to tell her treatment team that she had new experiences that worried her, but they did not react to this. She decided to seek help elsewhere and asked her father to drive her to the hospital. She was
RQ1 - Theme: Step 4. Making contact - Worrying about seeking helpPatient 3 experienced severe difficulties in making contact with the selected source of help once the decision to act was made. Patient 4 also experienced some difficulties. He had been taken into police custody after an episode on a public bus where he was behaving “ crazy” because he was hallucinated. When
RQ1 - Theme : Step 5. Disclosure - Others not reactingNone of the patients described any difficulties in disclosing their problems. Several of them did, however, describe difficulties with not truly being understood by neither laymen nor professionals. For example, Patient 7 told her mother that she was hearing people who were not present talking to her. Her mother responded to her by saying that it was probably just ghosts, and she did not return to the issue or take any kind of action in relation to this. The patient described that after this, she did not seek help for a long time.“ When you are not taken seriously the first time, then why should I pursue it any further?” Patient 3 told the staff at the psychiatric clinic, where she was already in
RQ2 - Theme: Insight into illnessThe degree of insight into illness affected the identification of the problem and thus the source the patients chose to seek help from. Insight into illness seemed to span a continuum from adamantly ascribing all hardship to the actions of external persecutors to considering if some kind of mental disorder might play a role. For example, Patient 8 explained that he had been “ hearing voices” since he was 15 or 16 years old, and that for many years they had provided him
RQ2 - Theme: Double bookkeepingSeveral of the patients uttered statements indicative of double bookkeeping as first described

Macnaughton et al. (2015)
Theme: Becoming demoralizedParticipants typically attributed initial phenomenological changes of psychosis to some plausible explanation that was relatively benign, in an attempt to minimize or normalize the experience. For instance, one participant, despite feeling that her friends were “ pulling a plot” on her, felt it “ was just depression” . Another person talked about feeling “ really paranoid” , but attributed this to having “ an emotional problem” , which he sought to deal with through
Theme: Experiencing an impactAuthors reported that people may have come to understand these symptoms as part of a mental illness after a positive expereince with the medication. As one young woman explained: “ when the medication works … the thing is: the type of difference it makes, makes you doubt your previous state. You start to [wonder] … maybe that wasn’ t
Theme: Finding a fitParticipants may also come to accept the notion of illness as a plausible explanation when they make comparisons and sense a fit between their own experiences and the information about illness they eventually come across through their interactions with mental health professionals, and through their interactions with other people to whom similar diagnoses have been applied. Authors noted that initially the information may be unconvincing given the salience of the psychosis experience.“ no matter how many times people told me that, even when I got a little bit better, I still thought that those demons were real, because they were such a real experience.” The scepticism may also relate to the meanings ascribed to
Theme: Envisioning illness in the background of lifeParticipants described a range of emotional responses to their initial awareness ofthe possibility of illness. In general, those whose lives were perceived as going offtrack and who had exhausted alternative explanations were more inclined to berelieved upon learning they had an illness

Bogen-Johnston et al. (2019)
Theme: Effect of disclosure on the selfParticipants gave much consideration to the pros and cons of disclosure. This often entailed a process whereby the presence of voices had to be acknolwedged, which also meant coping with the embarrasment of being a voice hearer and identifying someone who has mental health issues.In many cases, seeking help was not initiaed until it became necessary and voices could no longer be endured alone.Note: Authors only introduced subthemes and their overall
Subtheme: What problem?7/20 participants expressed denail of voices or that voices were an issue, part of the process of discussing voices involved acknowledging that a problem existed. However, as the distress and a battle with voices continued, accepting their presence could no longer be avoided. Participant 17 came to realize that in order to obtain relief, they needed
Subtheme: I feel too ashamed5/20 participants described how their understanding and perception of voices was wither a barrier or an enabler to disclosure.For some, beliefs about what it meant to hear voices evoked feelings of shame. The self-stigmatization of identifying as “crazy” meant that hearing voices was an embarrassing experience best concealed:"Did you tell anybody? No! No, I felt really ashamed ‘cause you know when you think “ah, you’re hearing voices” you felt a bit crazy and mental you know. So I kept it for myself for a very long time. It’s not ‘til erm, I told. I didn’t tell my mu- I didn’t tell my family for months, and months, and months. I kept it to myself."For other participants, awareness of self-stigmatization
Subtheme: Reaching desperation10/20 participants reported reaching a point of desperation where they felt a need to disclose negative feelings associated with the voices despite feeling ashamed. As voices continued, a vital point in the journey was reached: hearers felt that they had no other alternative but to disclose their experiences, enabling them to seek professional help and support from others. According to the authors, in some cases, talking about these experiences helped faciliate discussions with others. For example, for P9, low self-worth, shame, and helplessness reached a stage whereby voices no longer acted as a barrier to disclosure: "That’s when I had to sort of tell them because I couldn’t hold it in anymore, like I had to tell someone.
Theme: Effect of disclosure on othersIn weighing up whether voices should be revealed, many interviewees considered the potential impact of disclosure upon others: the needs of others and the reactions of others.Note: Authors only introduced subthemes and their overall interpretation; no other information (e.g. quotes) was provided
Subtheme: Concerns about others5/20 participants worried that disclosure would cause anguish and place a burden on significant others in their lives, so revealing voices was not always thought of as a feasible option: "Did you tell anybody about it? No! Why not? I wanted to help myself. I wanted to get rid of it myself instead of putting the burden on other people."Most participants disclosed their voices to significant others such as parents or partners, but only after a period of time. However, P19’s sense of responsibility to his family meant that they were entitled to know about his voices at onset: "I think I left it about an hour after it [voice onset]… I sat upstairs by myself trying to make sense of things, trying to figure out what was going on. Then just decided: “No! Nothing’s working.” Sort of called my mum, my dad; went straight down the urgent treatment center at the
Subtheme: How will they respond?13/20 participants reported that the anticipation of others may react affected most of their decisions to disclose; other people's experiences, understanding, and attitudes towards mental health functioned to either encourage or discourage participant's willingness to reveal and discuss their voices. In some cases, according to authors, the
Theme: Help-seeking3/20 participants reported that social circumstnaces influenced their beliefs about the availability of others and whether disclosure was a viable option: "I never said anything ‘cause I never had nobody to tell really. Like at what, and I was, a partner or anything like that. I wasn’t close to my family. My mum and dad had just been divorced and it was just, there was so much going on I didn’t feel I was able to talk to anybody at the time."For some participants, help from others was not the norm because of past experience and/or gender stereotypes. Despite struggling with his voices, P18 was uncomfortable sharing personal experiences. He had never been shown how to, or acquired the language to, express his feelings: "I just found it

Melton et al. (2020)
Theme: Core Categories - Recognition of Symptoms and Presence or Absence of Supportive OthersRecognition of symptoms was the primary driver of helpseeking in this study, and this was influenced by type of symptom or sign as well as the presence or absence of supportive others, which in most cases was regular family contact. In contrast, absence of supportive others in the individual’s life prolonged the DUP. "Well yeah, before [arrest] it was like a year. Things were like happening, and people
Theme: Signs and symptomsThe core categories of recognition of symptoms and presence of supportive others were found to be influenced by symptom-type and signs of physical deterioration. Across cases the emergency of first positive symptoms (e.g. hallucinations, delusions) prompted recognition by the individual or supportive others according to others (Note: authors did not
Subtheme: Hallucinations-Only Facilitated RecognitionParticipants reported recognizing that they knew there was "something wrong" when recounting hallucations-only as the first positive symptom. They usually told a parent or existing counseling professional (n=3) (Note: not clear if 3 participants reported or if only 3 told a counseling professional or parent). "I’d already spent a couple days on the phone with my mom, not really knowing what to do, …she’s the one who mentioned, look, if it gets bad enough, you need to just check yourself into the hospital. So I went."Two additional participants confided in their existing professional helpers (e.g. counselors) that they were hearing voices, which prompted the professional helpers to make a referral
Subtheme: Presence of Delusions Complicated RecognitionIn most cases where delusions were present either alone (n = 2) or mixed with hallucinations (n = 4) as the first positive symptoms, participants reported that the individual recognition of a psychotic symptom was absent, and thus an external person was the first to come to recognize the delusion as psychosis. "I didn’t think about it reasonably, like scientifically or even like objectively or straightforward. I wasn’t questioning why I was thinking that way because I was just thinking that way. It was more like I was believing in this certain way, I wasn’t thinking in a certain way."Family members in our study misinterpreted delusional symptoms as behaviors or symptoms of a mood disorder
Theme: Physical Deterioration Prompts Action by FamilyIn 2 cases, delusions were present and fmaily delayed taking action; "visibility" of a physical deteroriation led to help-seeking. "I knew it wasn’t…something…why was he doing this? I didn’t understand why…it just didn’t seem like, if you want to call it normal behavior. About a few nights later again we couldn’t
Theme: Arrest Facilitates Action2 participants reported that getting arresting while acting on their command hallucations or delusional thoughts happened before recognition of symptoms and ended the DUP through psychiatric treatment.

Judge et al. (2008)
Theme: Recognizing changes - "It was normal"Most participants (N=11) initially perceived experiences like hallucation as "normal" and part of who they were.“ I thought that was just the way I was.” “ The doctors asked [about voices], but I related it to my actual self. It was that close.” For participants, changes were readily assimilated into the self rather than immediately recognized as an illness, a process known as normalizing.The participants’ normalizing work may reflect a complicated fusion
Theme: Recognizing changes - "explanatory models" All participants generated "explanatory models" of the changes they experienced. No participant attributed changes in the self to mental illness before receiving a psychiatric diagnosis, which is consistent with past reports. 12 participants attributed chnages to psychosocial events; for example, stress and cultural
Theme: Responding to changes - Withdrawal or social isolationRefers to the ways that participants responded to changes in themselves, which included, but are not limited to, help-seeking behaviors.9 participants described withdrawal as a way to cope. Withdrawal or social isolation is associated with lengthier periods of untreated psychosis. Responses suggest that withdrawal functioned as a way to manage aberrant experiences privately, in part because of the difficulty of explanaing their experiences to others. “ When I think I have the flu coming on, I can tell somebody. But I have no prior experience of psychosis . . . I couldn’ t say ‘ I think this is what is going on with me.’ ” “ I tried to help myself. I stayed in solitary for six months in a motel
Theme: Responding to changes - Avoiding help5 participants described stigma concerns as a barrier to help-seeking.Avoiding help was one way that participants expressed awareness of schizophrenia as a stigmatized illness.These reports underscore that even when experiencing psychosis, participants accurately perceived prevailing stigmatizing attitudes about schizophrenia.“ Because everyone would think you was crazy. . . . I don’ t want people to be paranoid around me.” “ I wouldn’ t tell anyone about the voices. It never felt safe to do that. I pictured myself being locked up in a cell if I told the truth.”
Theme: Coming to terms with psychosis All participants described coming to terms with psychosis. For example, receiving a diagnosis of schizophrenia altered what participants hoped to achieve in life.“ I want to have a nice job, I want to get married, I want to have a family, I want to be a normal person, like everyone, but schizophrenia doesn’ t help with that.Another dimension

Appendix G. Full table of translating and synthesizing tables

Source	Spikol & Murphy (2019)	Singh et al. (2013)
Themes	Age of onset	The importance of family in help-seeking "Carer: We do like . . . it' s not an exorcism or nothing. It' s just kind of like a blessing. We took him to all sorts of Maulvis [cleric] and stuff and paid a lot of money and stuff."
Themes	Auditory hallucinations "The theme of universal experience emerged in those with childhood onset as they assumed that their experience of hearing voices was common"	Ethnic differences in the appraisal of low-level (non-psychotic) psychological distress
Themes	Voice personification and characteristics -- unclear how much insight participants hand as voice identity became more salient	Religion and culture as frameworks for help-seeking decisions
Themes	Visual hallucinations Some experienced visual hallucinations related to and reinforcing pre-existing delusions, and several described immersive, multi-modal hallucinations	Stressful life events as attributions, which prevent medical help-seeking "He had struggled with diabetes, was not doing well at school, his
Themes	Paraonia 30% reported paranoid ideation; common theme was being the victim of the	Ethnic differences in personal and family coping "The way I dealt with it at the time was a lot like, because I know I can
Themes	Delusions 4 referenced the film "The Truman Show" - life as a simulation where every	Crisis point as an important variable in help-seeking
Themes	Insight Majority of sample discussed gaining insight in reference to experiences. 43%	Ambivalence: competing and contrasting explanatory models
Themes		Mistrust or suspicion of services The lack of availability of beds, an unfamiliar hospital environment
Themes		
Themes		
Themes		
Classifications	Orange **Initial certainty of experiencies** -- *Contextualising history and recent experiences* -- *"I thought it was normal"/transient*	Blue **Cognitive confusion/incositencies increases uncertainty** -- *Self-reliance strategies* -- *Role of information campaigns on increasing/decreasting certainty and/or confusion*

Bay et al. (2016)	Jansen et al. (2015)
Failure to recognize symptoms of psychosis Majority of participants reported failing to understand they needed help during onset, but instead believed symptoms and changes would disappear on their own without intervention	Stigma and fear of the psychiatric system as barriers to help seekingCould be caterogized as either "role of services" or "initial certainty""I think I still had Breivik in my head, you know, and the guy is nuts, and then I' m sitting there thinking, ' shit, I don' t want to be in the same category as such a bastard""I used to rationalize everything I experienced (psychotic symptoms) . . . like ' it' s hot today, I haven' t had enough to drink"
Difficulties expressing their experiences - Includes expressing difficulties to services so may move this to "the role of services"	The impact of traumatic experiences on the experience and development of psychosis"I was also bullied in school, and that made it worse, I was very temperamental, because it was difficult to control the voices and all, so I often ran amok."
Concerns about stigma	The importance of significant others"They' ve just been there the whole time, they don' t really have to do much, they' ve just been there."
Poor psychosis detection skills among health-care professionals More than half of the participants reported that healthcare professionals failed to recognize symptoms as psychosis.	The experience of safety and trusting the early detection team"They were listening and came up with suggestions, because I' m having difficulties opening up, so they were fishing in the right way. They were calm and took all the time needed."
Lack of awareness or understanding of TIPS and TIPS Information-campaigns "I was thinking it had gone so far that there was nothing to be done about it anyway	The relief of receiving a diagnosis"I thought it was great to receive a diagnosis. Then you know ' okay, this is what' s wrong with you' , instead of being left in the dark."

Pink

<u>The importance of signficant others in facilitating/delaying help-seeking</u>

-- *Familial framework*

-- *Challenges in offering/finding support*

Green**<u>Needing a more sophisiticated framework to explain experiences</u>**-- *Religius/cultural framework*-- *Victim of persecution/society framework*

Jansen et al. (2014)	Tanskanen et al. (2011)	Hardy et al. (2020)	Ferrari et al. (2018)
Facilitating help-seeking - Support from significant others in initiating helpseeking process	Understandings of symptoms and experiences - attributions of symptoms Could be under "initial certainty" or "cognitive confusion"	Perceptions of stigma	Women' s barriers to EI services: the role of female stereotypes"It' s like, you have to reach rock bottom before someone will help you"
Facilitating help-seeking - Internet as a source of information of	Understandings of symptoms and experiences- Response to symptoms Almost half the service users (n=10) described that they	Shame and fear “ Lack of mental health parity and its personal	Feeling ignored and mistrustedWomen felt that family members and health-care providers often dismissed their calls for help, as they perceived it as an attempt to gain attentionRole of services or importance of significnat others?
Barriers to help-seeking - Fear of stigma and self-stigma	Help-seeking processes Service users and carers describe change over time and ambivalence in their response to difficulties	Outcomes associated with stigma "Accepting treatment meant I	Being labelled as ' overdramatic' or a “ drama queen"
Barriers to help-seeking - Symptoms viewed as normal or lack of knowledge	Unawareness of problems Note: Described remaining unaware of their symptoms of psychosis until they made contact with mental health	Criminalization "The court system criminalized his obvious	Being ' too functional' Women recounted how being identified as ' too functional' by healthcare providers became a barrier to timely access to EI services
	Attribution of problems to mental illness These respondents appeared to recognise a need for	Isolation and/or alienation "His friends dropped having	Men' s barriers to EI services: Therole of male stereotypesMen who took part in the focus groups also described how gender stereotypes played a role in disclosing
	Other attributions of problems “ I thought okay there is something wrong with me	Relationship between stigma and treatment interfering behaviors	The need to be strong and in controlMen described how male stereotypes, such as men being strong, in control, and unable to look weak or vulnerable, stopped them from disclosing
	Beliefs and knowledge about mental health services - Stigma		Physicality and differences inresponses between gender"Some people told me I look REALLY SCARY when I' m psychotic. I' m a big guy, so, definitely I think there' d be more police
	Beliefs and knowledge about mental health services - lack of knowledge		
	Responses of social networks to illness onset and helpseeking - Responses of immediate social networks		
	Responses of social networks to illness onset and helpseeking - Responses of community organisations Health professionals' responses		
		Yellow **Theme: Reaching a crisis point** *-- Recognizing/confirming psychosis*	Red**The role of services in facilitating/delaying help-seeking**-- *"Fragmented transitions -- Positive experiences with pathways-- Negative experiences with pathways*

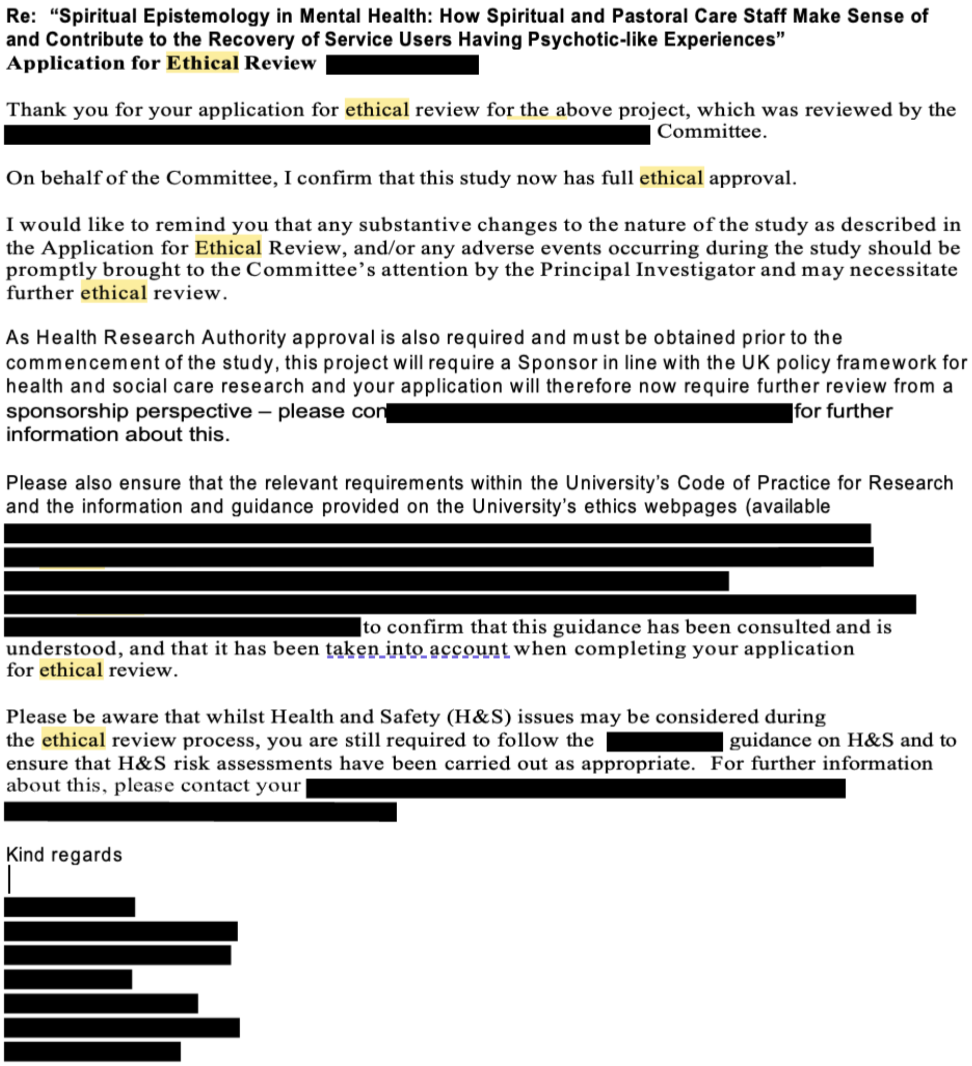
Nordgaard et al. (2020)	Cabassa et al. (2018)	Kamens et al. (2018)
RQ1- Step 1. Recognition and identification of the problem "She had a vague idea that the purpose of this whole set up was to expos her on television"	Client/family factors - Attribution of symptoms	Life pre-duration of untreated psychosis - Daily life as unremarkableNote: Experiences were described as positive and supportive
RQ1 - Involving others in identifying the problem	Client/family factors - Self-reliance This was often driven by uncertainty about what they were experiencing,	Life pre-duration of untreated psychosis - Existential concerns about life as a young adult
RQ1 - Step 2. Deciding to act Social problems	Client/family factors - Stigma	Life pre-duration of untreated psychosis - For some, struggles started early
RQ1 - Physical problems e.g., went to see the school counsellor at the behest of her boyfriend and stated that had it not been for his	Client/family factors - Cloud of uncertainty	The onset of challenges - Implicit conceptualizations of onsetNote: overwhelming challenge(s) that disrupted previously mundane daily lives
RQ1 - Step 3. Selection of source of help Involving the authorities	Healthcare factors - Interpersonal connections	The onset of challenges - Meanings of DUP within TSD (trajectory of subjective difficulties)For all participants, the onset of psychotic experiences (i.e.
RQ1 - Urgent need for help	Healthcare factors - Quality of care	The onset of challenges - Negative Pathways to Care
RQ1 - Step 4. Making contact - Worrying about seeking help	Healthcare factors - Family involvement	Experiences during TSD and DUP - obstacles to independence
RQ1 Step 5. Disclosure - others not reacting	Healthcare factors - Care transitions	Experiences during TSD and DUP - Feeling distant and different from othersFor all participants, the TSD and DUP were characterized by feelings of
RQ2 -Insight into illness Insight into illness seemed to span a continuum from		Experiences during TSD and DUP - Spiritual–existential and social justice concerns
RQ2 - Double bookkeeping Note: refers to the phenomenon that many patients with		Perceptions of supportNote; Believing stronger social report would have benefited them
		Life post-DUP

Bogen-Johnston et al. (2019)	Macnaughton et al. (2015)
Effect of disclosure on the self In many cases, seeking help was not initiaed until it became necessary and voices could no longer be endured alone.	Becoming demoralized"I eventually, to make sense of my paranoid delusions, came up with a rationale that my head (mind) was the centre of a[n] on-line reality show that prayed on my deep sense of intuitiveness. […] Obviously when this began I was very afraid, self conscious and the like, but eventually [I] accepted [this] as normal.
What problem? "It didn’ t have a big massive impact on my life really."	Experiencing an impact
I feel too ashamed Could be "concerns about others perceptions" or double book-keeping	Finding a fit
Reaching desperation	Envisioning illness in the background of lifeIn general, those whose lives were perceived as going offtrack and who had exhausted alternative explanations were more inclined to berelieved upon learning they had an illness
Effect of disclosure on others Note: many interviewees considered the	
Concerns about others Note: participants worried that disclosure	
How will they respond? Note: participants reported that the	
Help-seeking Could be "importance of significant	

Judge et al.	Melton et al. (2020)
Recognizing changes - "It was normal"	Recognition of Symptomsand Presence or Absence of Supportive Others
Recognizing changes - "explanatory models"	Signs and symptomsAcross cases the emergency of first positive symptoms (e.g. hallucinations, delusions) prompted recognition by the individual or supportive others according to others (Note: authors did not provide if "across cases" means some, majority, or few participants). However authors also noted that a diferent trajectory of recognition unfolded when delusions were present in comparison to those
Responding to changes - Withdrawal or social isolation	Hallucinations-Only Facilitated Recognition
Responding to changes - Avoiding help	Presence of Delusions Complicated Recognition-- insight from a significant other was important for recognition otherwise the participant had alternative explanations-- importance of significant others or sophisticated framework?
Coming to terms with psychosis	Physical Deterioration Prompts Action by Family
	Arrest Facilitates Action

Appendix H. Ethical approval letters (Portions redacted to maintain confidentiality and anonymity)

a)



Re: "Spiritual Epistemology in Mental Health: How Spiritual and Pastoral Care Staff Make Sense of and Contribute to the Recovery of Service Users Having Psychotic-like Experiences"
Application for Ethical Review [redacted]

Thank you for your application for ethical review for the above project, which was reviewed by the [redacted] Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

As Health Research Authority approval is also required and must be obtained prior to the commencement of the study, this project will require a Sponsor in line with the UK policy framework for health and social care research and your application will therefore now require further review from a sponsorship perspective – please con[redacted]for further information about this.

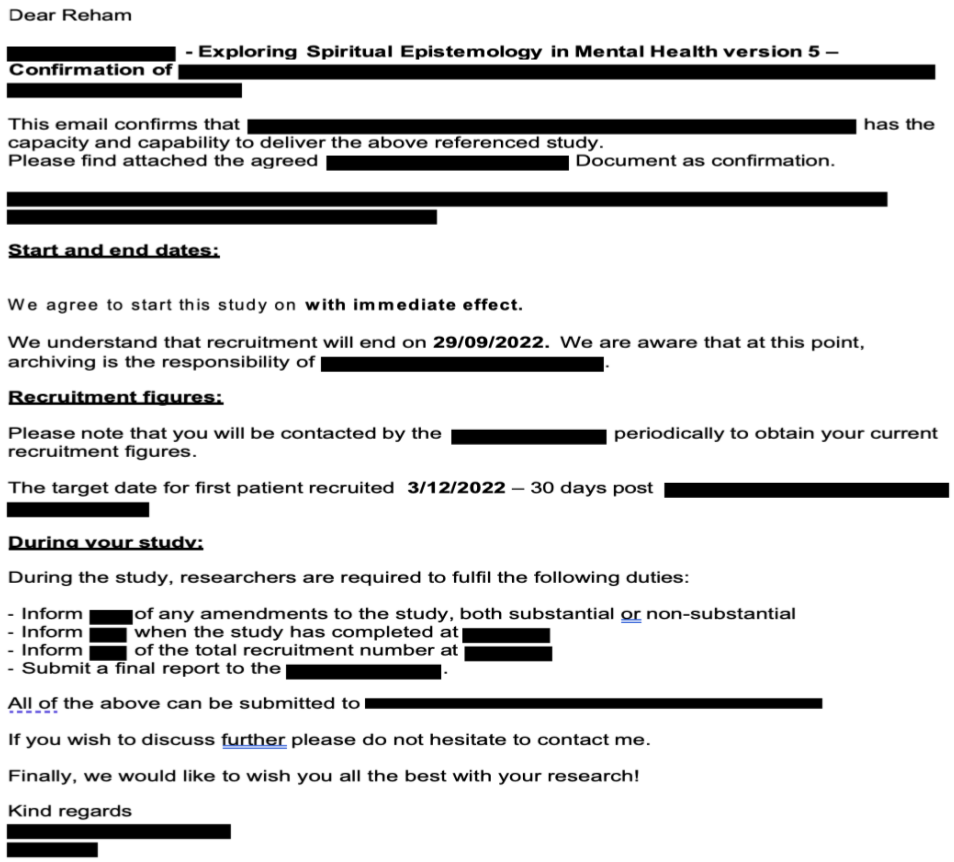
Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available [redacted] to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the [redacted] guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your [redacted]

Kind regards

[redacted]

b)



Dear Reham

[redacted] - Exploring Spiritual Epistemology in Mental Health version 5 – Confirmation of [redacted]

This email confirms that [redacted] has the capacity and capability to deliver the above referenced study.
Please find attached the agreed [redacted] Document as confirmation.

[redacted]

Start and end dates:

We agree to start this study on **with immediate effect.**

We understand that recruitment will end on **29/09/2022.** We are aware that at this point, archiving is the responsibility of [redacted].

Recruitment figures:

Please note that you will be contacted by the [redacted] periodically to obtain your current recruitment figures.

The target date for first patient recruited **3/12/2022** – 30 days post [redacted]

During your study:

During the study, researchers are required to fulfil the following duties:

- Inform [redacted] of any amendments to the study, both substantial or non-substantial
- Inform [redacted] when the study has completed at [redacted]
- Inform [redacted] of the total recruitment number at [redacted]
- Submit a final report to the [redacted].

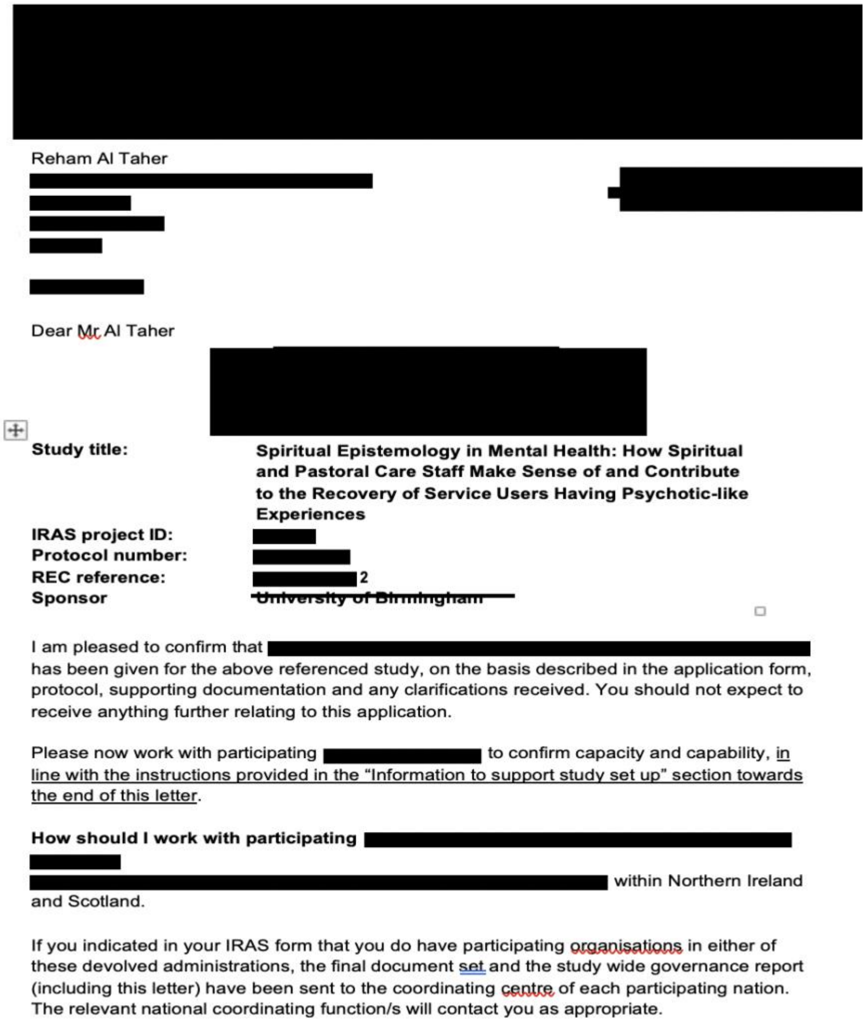
All of the above can be submitted to [redacted]

If you wish to discuss further please do not hesitate to contact me.

Finally, we would like to wish you all the best with your research!

Kind regards
[redacted]

c)



[redacted]

Reham Al Taher
[redacted]

[redacted]

[redacted]

Dear Mr Al Taher

[redacted]

Study title:	**Spiritual Epistemology in Mental Health: How Spiritual and Pastoral Care Staff Make Sense of and Contribute to the Recovery of Service Users Having Psychotic-like Experiences**
IRAS project ID:	[redacted]
Protocol number:	[redacted]
REC reference:	[redacted] **2**
Sponsor	~~**University of Birmingham**~~

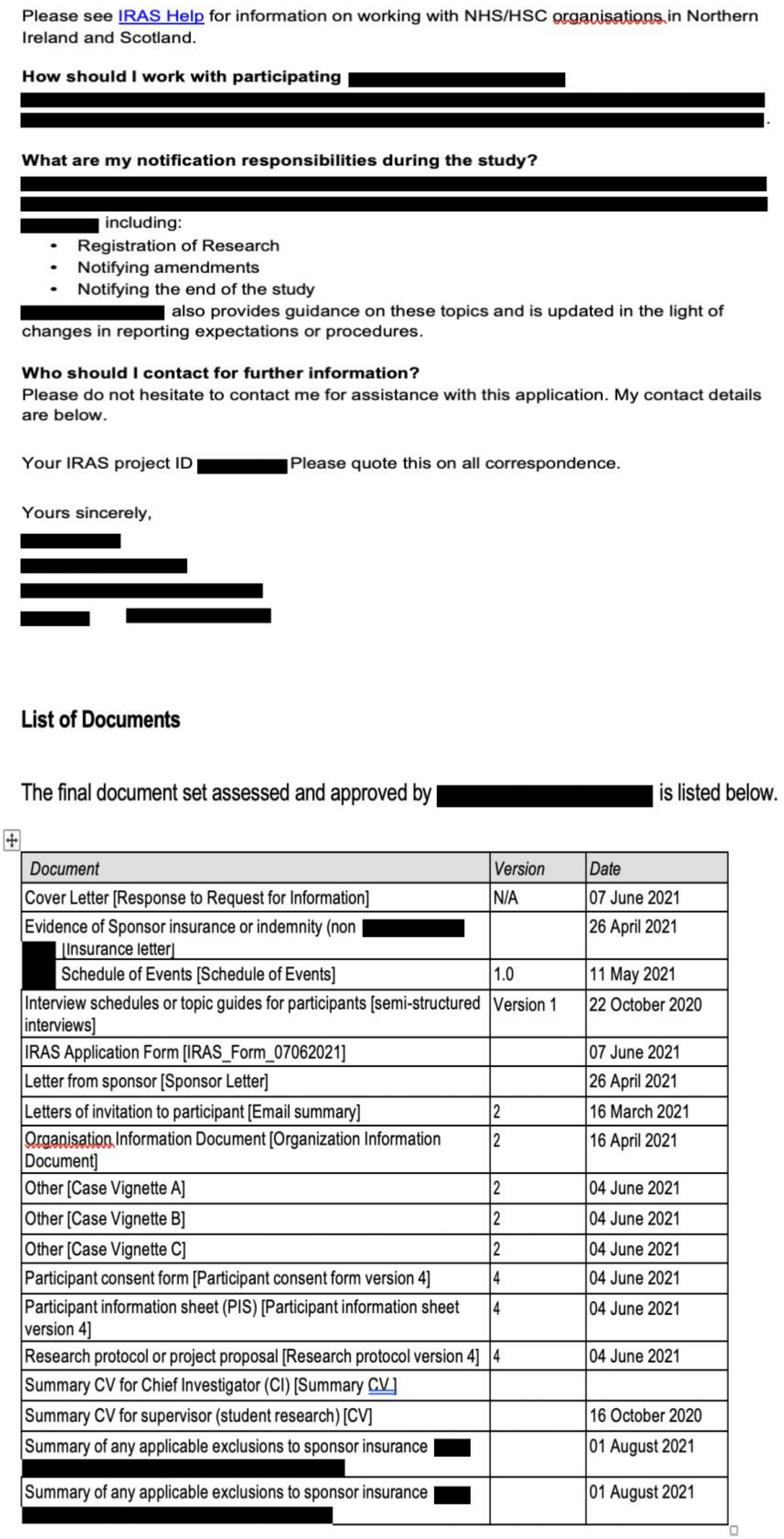
I am pleased to confirm that [redacted] has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating [redacted] to confirm capacity and capability, <u>in line with the instructions provided in the “Information to support study set up” section towards the end of this letter</u>.

How should I work with participating [redacted]

[redacted] within Northern Ireland and Scotland.

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



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

How should I work with participating [redacted].

What are my notification responsibilities during the study?

[redacted] including:

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

[redacted] also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

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

Your IRAS project ID [redacted] Please quote this on all correspondence.

Yours sincerely,

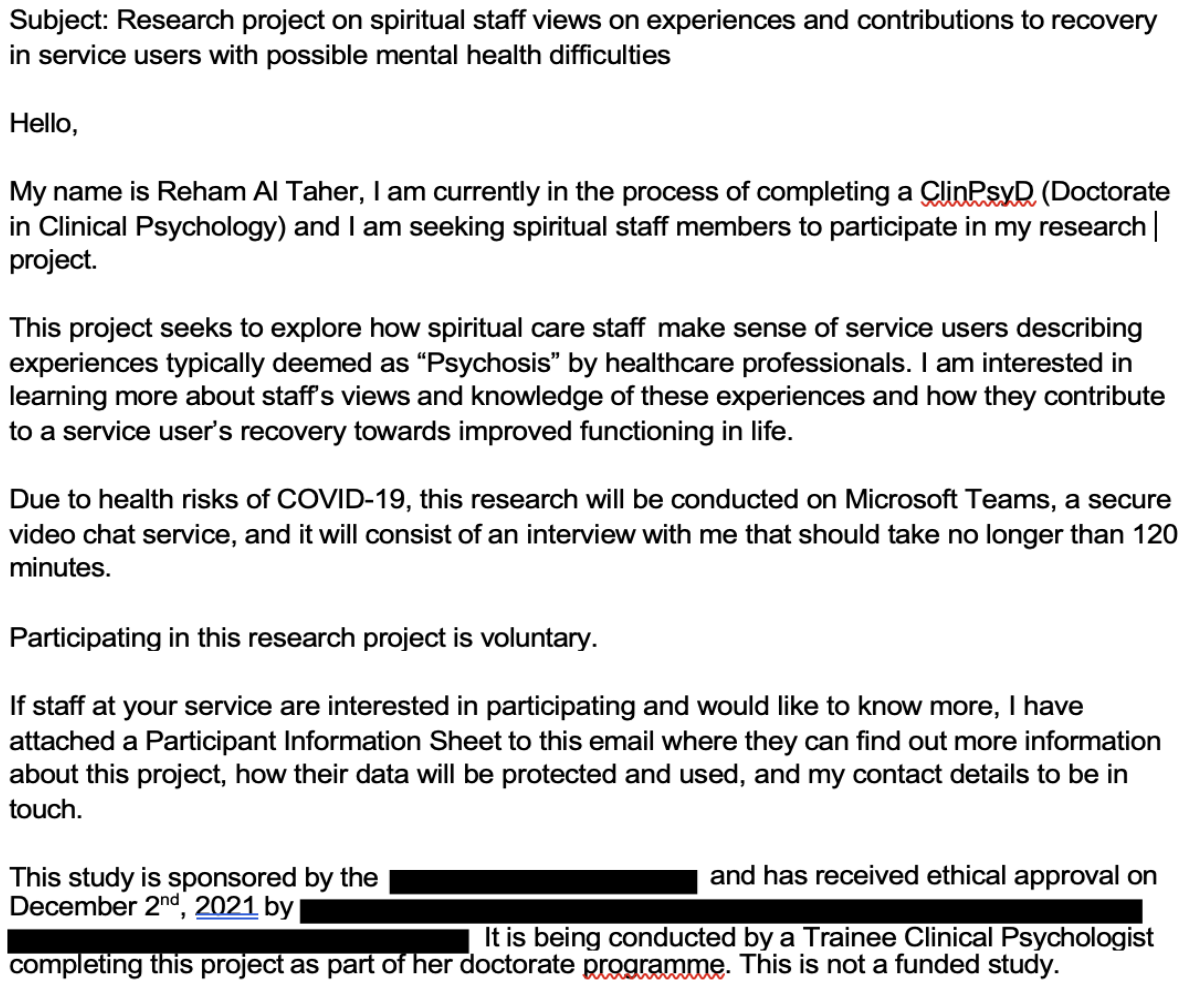
[redacted]

List of Documents

The final document set assessed and approved by [redacted] is listed below.

Document	*Version*	*Date*
Cover Letter [Response to Request for Information]	N/A	07 June 2021
Evidence of Sponsor insurance or indemnity (non [redacted] [redacted] [Insurance letter]		26 April 2021
[redacted] Schedule of Events [Schedule of Events]	1.0	11 May 2021
Interview schedules or topic guides for participants [semi-structured interviews]	Version 1	22 October 2020
IRAS Application Form [IRAS_Form_07062021]		07 June 2021
Letter from sponsor [Sponsor Letter]		26 April 2021
Letters of invitation to participant [Email summary]	2	16 March 2021
Organisation Information Document [Organization Information Document]	2	16 April 2021
Other [Case Vignette A]	2	04 June 2021
Other [Case Vignette B]	2	04 June 2021
Other [Case Vignette C]	2	04 June 2021
Participant consent form [Participant consent form version 4]	4	04 June 2021
Participant information sheet (PIS) [Participant information sheet version 4]	4	04 June 2021
Research protocol or project proposal [Research protocol version 4]	4	04 June 2021
Summary CV for Chief Investigator (CI) [Summary CV]		
Summary CV for supervisor (student research) [CV]		16 October 2020
Summary of any applicable exclusions to sponsor insurance [redacted] [redacted]		01 August 2021
Summary of any applicable exclusions to sponsor insurance [redacted] [redacted]		01 August 2021

Appendix I. Email summary that was sent to the manager of spiritual care at a UK mental health service (Portions redacted to maintain confidentiality and anonymity)



Subject: Research project on spiritual staff views on experiences and contributions to recovery in service users with possible mental health difficulties

Hello,

My name is Reham Al Taher, I am currently in the process of completing a ClinPsyD (Doctorate in Clinical Psychology) and I am seeking spiritual staff members to participate in my research project.

This project seeks to explore how spiritual care staff make sense of service users describing experiences typically deemed as “Psychosis” by healthcare professionals. I am interested in learning more about staff’s views and knowledge of these experiences and how they contribute to a service user’s recovery towards improved functioning in life.

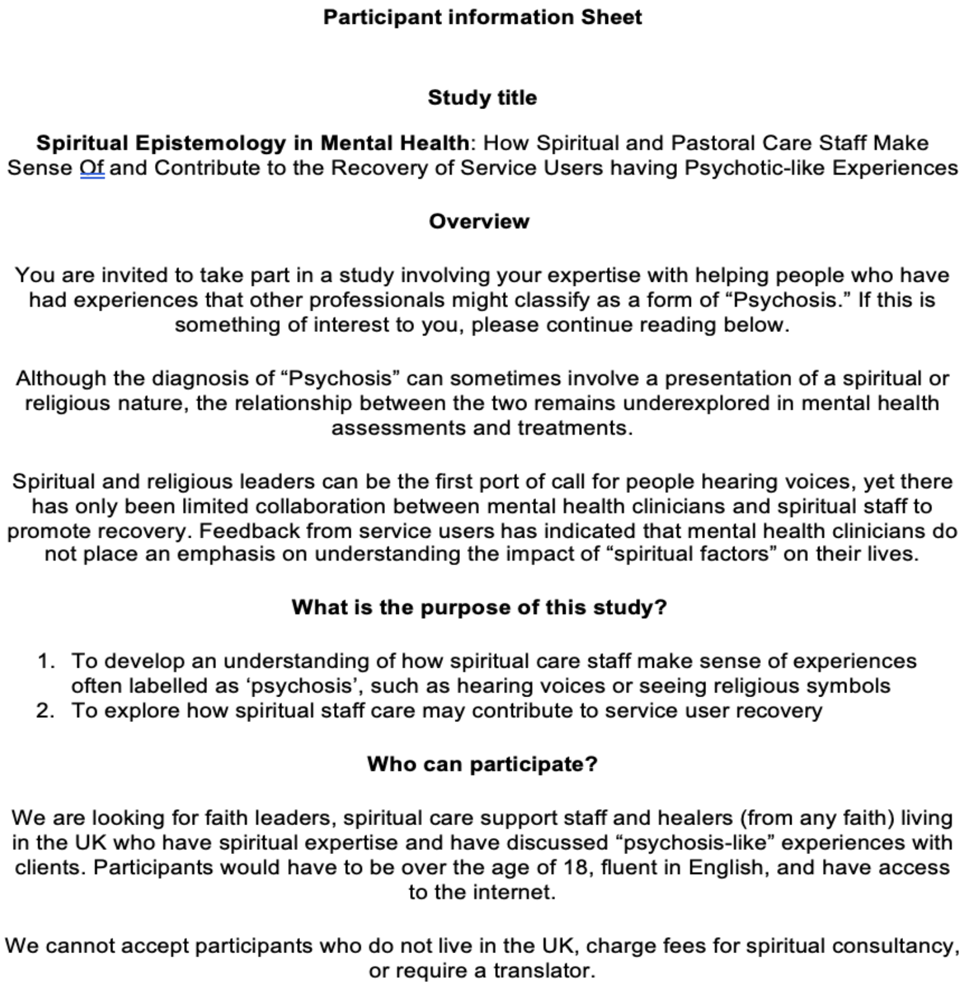
Due to health risks of COVID-19, this research will be conducted on Microsoft Teams, a secure video chat service, and it will consist of an interview with me that should take no longer than 120 minutes.

Participating in this research project is voluntary.

If staff at your service are interested in participating and would like to know more, I have attached a Participant Information Sheet to this email where they can find out more information about this project, how their data will be protected and used, and my contact details to be in touch.

This study is sponsored by the [redacted] and has received ethical approval on December 2nd, 2021 by [redacted] It is being conducted by a Trainee Clinical Psychologist completing this project as part of her doctorate programme. This is not a funded study.

Appendix J. Participant Information Sheet (Portions redacted to maintain confidentiality and anonymity)



Participant information Sheet

Study title

Spiritual Epistemology in Mental Health: How Spiritual and Pastoral Care Staff Make Sense Of and Contribute to the Recovery of Service Users having Psychotic-like Experiences

Overview

You are invited to take part in a study involving your expertise with helping people who have had experiences that other professionals might classify as a form of "Psychosis." If this is something of interest to you, please continue reading below.

Although the diagnosis of "Psychosis" can sometimes involve a presentation of a spiritual or religious nature, the relationship between the two remains underexplored in mental health assessments and treatments.

Spiritual and religious leaders can be the first port of call for people hearing voices, yet there has only been limited collaboration between mental health clinicians and spiritual staff to promote recovery. Feedback from service users has indicated that mental health clinicians do not place an emphasis on understanding the impact of "spiritual factors" on their lives.

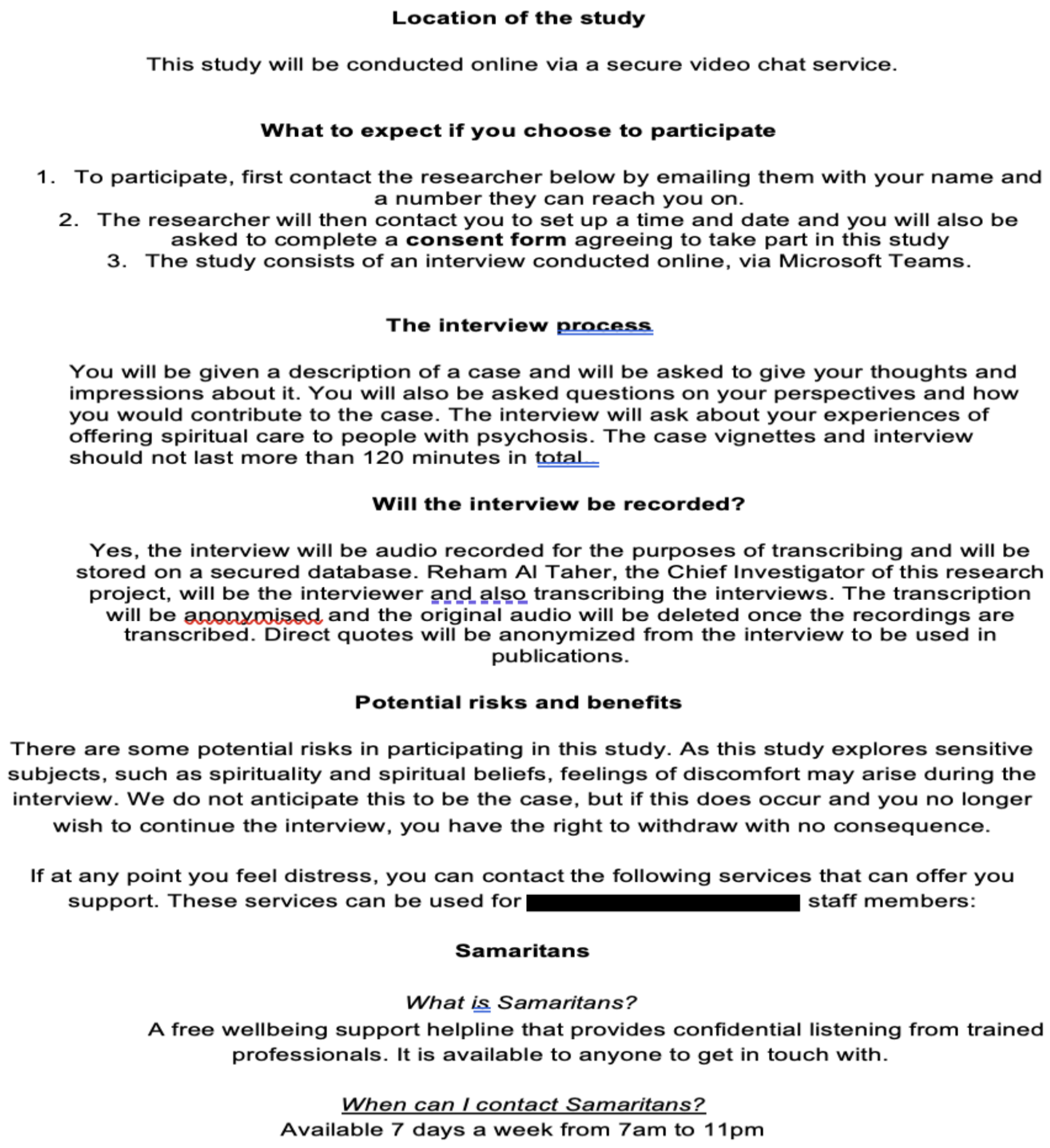
What is the purpose of this study?

1. To develop an understanding of how spiritual care staff make sense of experiences often labelled as 'psychosis', such as hearing voices or seeing religious symbols
2. To explore how spiritual staff care may contribute to service user recovery

Who can participate?

We are looking for faith leaders, spiritual care support staff and healers (from any faith) living in the UK who have spiritual expertise and have discussed "psychosis-like" experiences with clients. Participants would have to be over the age of 18, fluent in English, and have access to the internet.

We cannot accept participants who do not live in the UK, charge fees for spiritual consultancy, or require a translator.



Location of the study

This study will be conducted online via a secure video chat service.

What to expect if you choose to participate

1. To participate, first contact the researcher below by emailing them with your name and a number they can reach you on.
2. The researcher will then contact you to set up a time and date and you will also be asked to complete a **consent form** agreeing to take part in this study
3. The study consists of an interview conducted online, via Microsoft Teams.

The interview process

You will be given a description of a case and will be asked to give your thoughts and impressions about it. You will also be asked questions on your perspectives and how you would contribute to the case. The interview will ask about your experiences of offering spiritual care to people with psychosis. The case vignettes and interview should not last more than 120 minutes in total.

Will the interview be recorded?

Yes, the interview will be audio recorded for the purposes of transcribing and will be stored on a secured database. Reham Al Taher, the Chief Investigator of this research project, will be the interviewer and also transcribing the interviews. The transcription will be anonymised and the original audio will be deleted once the recordings are transcribed. Direct quotes will be anonymized from the interview to be used in publications.

Potential risks and benefits

There are some potential risks in participating in this study. As this study explores sensitive subjects, such as spirituality and spiritual beliefs, feelings of discomfort may arise during the interview. We do not anticipate this to be the case, but if this does occur and you no longer wish to continue the interview, you have the right to withdraw with no consequence.

If at any point you feel distress, you can contact the following services that can offer you support. These services can be used for [redacted] staff members:

Samaritans

What is Samaritans?

A free wellbeing support helpline that provides confidential listening from trained professionals. It is available to anyone to get in touch with.

When can I contact Samaritans?

Available 7 days a week from 7am to 11pm

How can I get in touch with Samaritans?

Telephone: 0800 069 6222

Shout 85258

What is Shout 85258?

A free, confidential text message support service by trained volunteers. It is available for anyone to get in touch with

When can I contact Shout 85258?

Available 24 hours a day

How can I get in touch with Shout 85258?

Text SHOUT to 85258 and you will receive an automated text asking about the nature of the problem. 5 minutes after, you will get a response from a trained Shout Volunteer and you can begin chatting for free.

What is consent?

As defined by the [redacted] consent means a person must "give permission before they receive any type of medical treatment, test or examination." This is an important part of ethics and human rights.

Consent has to be valid, voluntary and informed. This means that the person must have made the decision to participate and was not influenced or pressured by others. In order for consent to be informed, the person who chooses to voluntarily participate must have been given all of the information on what the study involves, its potential benefits and risks, how their data will be handled, and what will happen to their results if the study does or does not finish.

Consent has to also be given to someone that has the "capacity" to do so. This means that the person can only give consent if they understand the information given to them before they choose to participate.

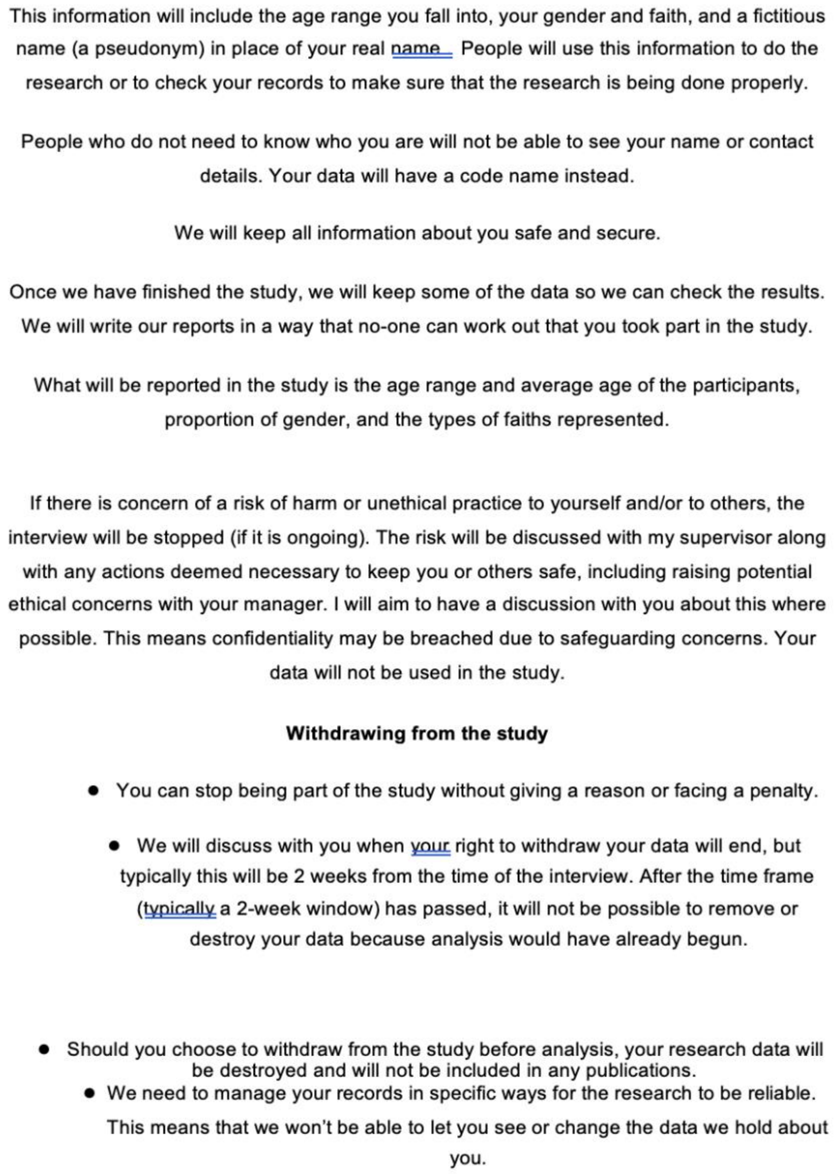
How will consent be given?

For this study, consent will be given in writing.

The researcher will email you an informed consent sheet. This must be completed and returned back prior to the interview.

Handling confidentiality

We will need to use some information from you for this research project.



This information will include the age range you fall into, your gender and faith, and a fictitious name (a pseudonym) in place of your real name. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code name instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What will be reported in the study is the age range and average age of the participants, proportion of gender, and the types of faiths represented.

If there is concern of a risk of harm or unethical practice to yourself and/or to others, the interview will be stopped (if it is ongoing). The risk will be discussed with my supervisor along with any actions deemed necessary to keep you or others safe, including raising potential ethical concerns with your manager. I will aim to have a discussion with you about this where possible. This means confidentiality may be breached due to safeguarding concerns. Your data will not be used in the study.

Withdrawing from the study

- You can stop being part of the study without giving a reason or facing a penalty.
- We will discuss with you when your right to withdraw your data will end, but typically this will be 2 weeks from the time of the interview. After the time frame (typically a 2-week window) has passed, it will not be possible to remove or destroy your data because analysis would have already begun.

- Should you choose to withdraw from the study before analysis, your research data will be destroyed and will not be included in any publications.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

What will happen to your results

All research data including your consent form and interview will be stored on secure servers owned by either the [redacted] .

The audio recording of your interview will be saved for the purposes of transcribing it. As soon as it is transcribed, the audio recording will be deleted.

This data will only be accessed by the principal investigator or members of the research team.

Since we are using pseudonyms instead of contact information in the study, a separate database with your assigned name to pseudonym will be saved. In line with the [redacted] guidelines on records management, necessary data, such as your consent form and transcription, will be kept for a period of 10 years from the date of collection.

Should you choose to withdraw from the study before analysis, your research data will be destroyed and will not be included in any publications.

The result of the study is expected to be published in a scientific journal.

As this study is not funded and is seeking only voluntary participants, participants will not be compensated for their involvement.

Data Protection and Data Controller

Under the Data Protection Act (2018) the [redacted] acts as the Data Controller in regulating the processing of "personal data" in relation to the individual.

Who is organizing this study? Has it received ethical approval?

This study is sponsored by [redacted] and has received ethical approval on December 2nd, 2021 by the [redacted] . It is being conducted by a Trainee Clinical Psychologist completing this project as part of her doctorate programme. This is not a funded study.

Complaints procedure

If you have any complaints in regards to the way you have been treated or for any other matter relating to the study you can write to the:

Name and expertise: [redacted]

[redacted]

Name and expertise: [redacted]

[redacted]

The [redacted] has in force a Public Liability Policy and/or Clinical Trials policy which provides cover for claims for "negligent harm" and the activities here are included within that coverage."

Where can you find out more about how your information is used

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to [redacted]
- by ringing us on [redacted]

If you would like further information and contact details

Name: Reham Al Taher,

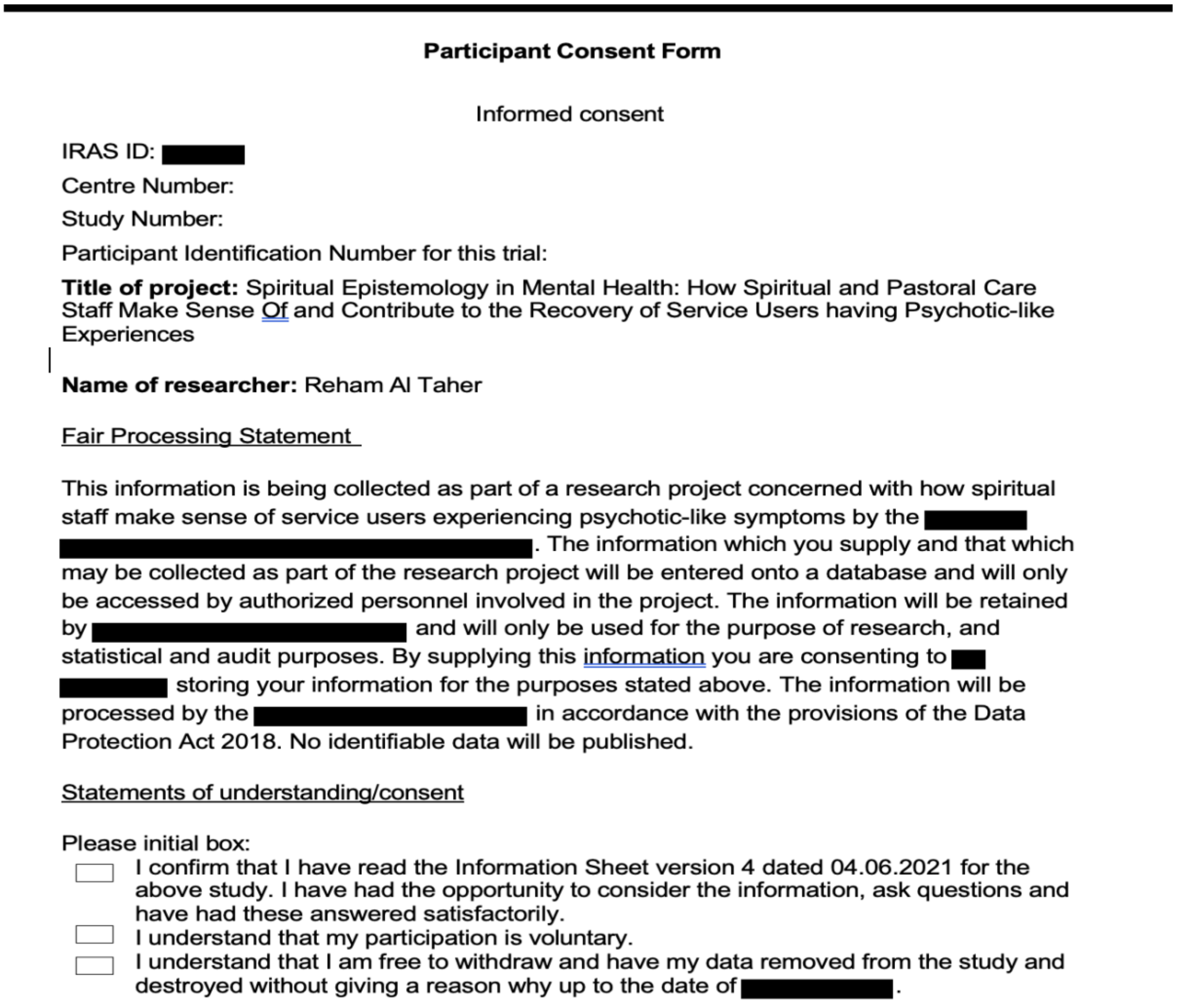
Trainee Clinical Psychologist and Chief Investigator

Email: [redacted]

Supervisor : [redacted]

[redacted]

Appendix K. Participant Consent Sheet (Portions redacted to maintain confidentiality and anonymity)



Participant Consent Form

Informed consent

IRAS ID: [redacted]
Centre Number:
Study Number:
Participant Identification Number for this trial:

Title of project: Spiritual Epistemology in Mental Health: How Spiritual and Pastoral Care Staff Make Sense Of and Contribute to the Recovery of Service Users having Psychotic-like Experiences

Name of researcher: Reham Al Taher

Fair Processing Statement

This information is being collected as part of a research project concerned with how spiritual staff make sense of service users experiencing psychotic-like symptoms by the [redacted]. The information which you supply and that which may be collected as part of the research project will be entered onto a database and will only be accessed by authorized personnel involved in the project. The information will be retained by [redacted] and will only be used for the purpose of research, and statistical and audit purposes. By supplying this information you are consenting to [redacted] storing your information for the purposes stated above. The information will be processed by the [redacted] in accordance with the provisions of the Data Protection Act 2018. No identifiable data will be published.

Statements of understanding/consent

Please initial box:

☐ I confirm that I have read the Information Sheet version 4 dated 04.06.2021 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
☐ I understand that my participation is voluntary.
☐ I understand that I am free to withdraw and have my data removed from the study and destroyed without giving a reason why up to the date of [redacted].

☐ I understand that once data analysis starts on the date of [redacted] will not be possible to withdraw and have my data removed from the study.

☐ I agree for the interview to be audio-recorded.

☐ I consent to anonymous quotes taken from my interview to be used in publications.

☐ I understand that the audio-recorded interview will be stored on [redacted] database according to the [redacted] Data Protection Act, as well as on [redacted] according to the [redacted]

☐ I understand that my personal data will be processed for the purposes detailed above, in accordance with the Data Protection Act 2018 with [redacted] acting as the Data Controller for my personal data.

☐ Based upon the above, I agree to take part in this study.

Name of participant	Date	Signature
Name of researcher/person taking consent.	Date	Signature

Appendix L. Pre-written interview questions and topic guides that was used during interview with participants

- A. Participant’s experiences of providing spiritual consultancy within a mental health framework
    1. Could you give me a brief description of how you got involved in spiritual work?
    2. Could you describe what usually happens in chaplain services, in your own words?
    3. What do you do as a [faith leader]?
    4. How do you feel when you are guiding someone on spiritual concerns? *(emotionally, physically, mentally)*
    5. What do you think about experiences that are difficult to explain in other kinds of ways, such as in science?
    6. If you had to describe what spirituality means to you, what words/images come to mind?
- B. Participants views on psychosis and current psychosis interventions
    1. What does the term “psychosis” mean to you?
    2. What do you think about the current way people with psychosis receive treatment?
    3. How have your experiences been in helping to manage people that have these experiences?
    4. What do you think is most important for recovery in psychosis?
- C. After the participant has read each case vignette
    1. How would you describe, in your own words, what is happening with this person?
    2. How would you explain the causes of this?
    3. How would you decide what to do with this person to help them through these difficulties?
    4. How would you offer your support?
    5. What do you know about experiences similar to this?
    6. What do you think the professionals in this case should do now?

Appendix M. An example of how the IPA step-by-step process was used with "Wilma"

Interpreted themes	Transcription:	Exploratory comments[5]
There is a place for science to exist in psychosis and spirituality/some things are unexplained It depends on the service user if they find scientific explanations helpful or not/framework-dependent Some service users find voices comforting/friendly/connected	**Wilma:** Yeah. Yeah. Yeah. That's it because I mean, you know, I don't know how far science has gone. But you know, you have the science fiction programs and they talk about different dimensions and things like that. And d'you know what, I'm open to that that quite possibly can exist, you know, and there are some things that are unexplained. Um [pause], But, I just I don't think it's very helpful sometimes. In fact, it depends on the service user. Because some people might hear and see things that other people can't and be totally freaked out by that. So they want medication and want it completely stopped, and then there are other people who will experience the same thing, and actually, as long as it's not disturbing them too much, they're not concerned. They actually quite enjoy it, they like the company, because I've had that as well. People will actually like the company, and if they've got, I don't know spirit guides or what they call spirit guides, or friends who are in spirit, they actually like it find them supportive. **Research Interviewer:** Yeah. And can you tell me more about how those experiences have been working with people who do who have received that label, who have heard voices? **Wilma:** Um, well, in what respect sort of the people who find them disturbing or? **Research Interviewer:** Uh, no how your experience has had been in working with someone who has experienced those things.	Is open and receptive to science and the different theory that can be discussed in science fiction Is unsure if it's helpful and says it depends on the service user; the benefit of science is dependent on the individual *Be totally freaked out by that*; these experiences can be anxiety-provoking to some Some service users who hear voices and want medication to make it stop and then there are those who are more accepting of it *Not disturbing them too much, they're not concerend*; reminds me of her saying that they're responsible for their body, so in that framework it's up to the person to decide if it's becoming "too much" *They like the company*; it can be enjoyable, comforting, friendly, and/or sense of connection *Spirit guides or what they call spirit guides;* guidance about someone's personhood and purpose whilst on earth and beyond. I wonder how spiritual/spirit guidance is defined compared to a spiritual practitioner – do they serve difference purposes? *Friends who are in spirit*; friendly spirits that offer them support. It's also about connection, closeness, and there's also a lack of hierarchal/power difference with that phrasing *Find them supportive*; experiencing support via voice-hearing experience

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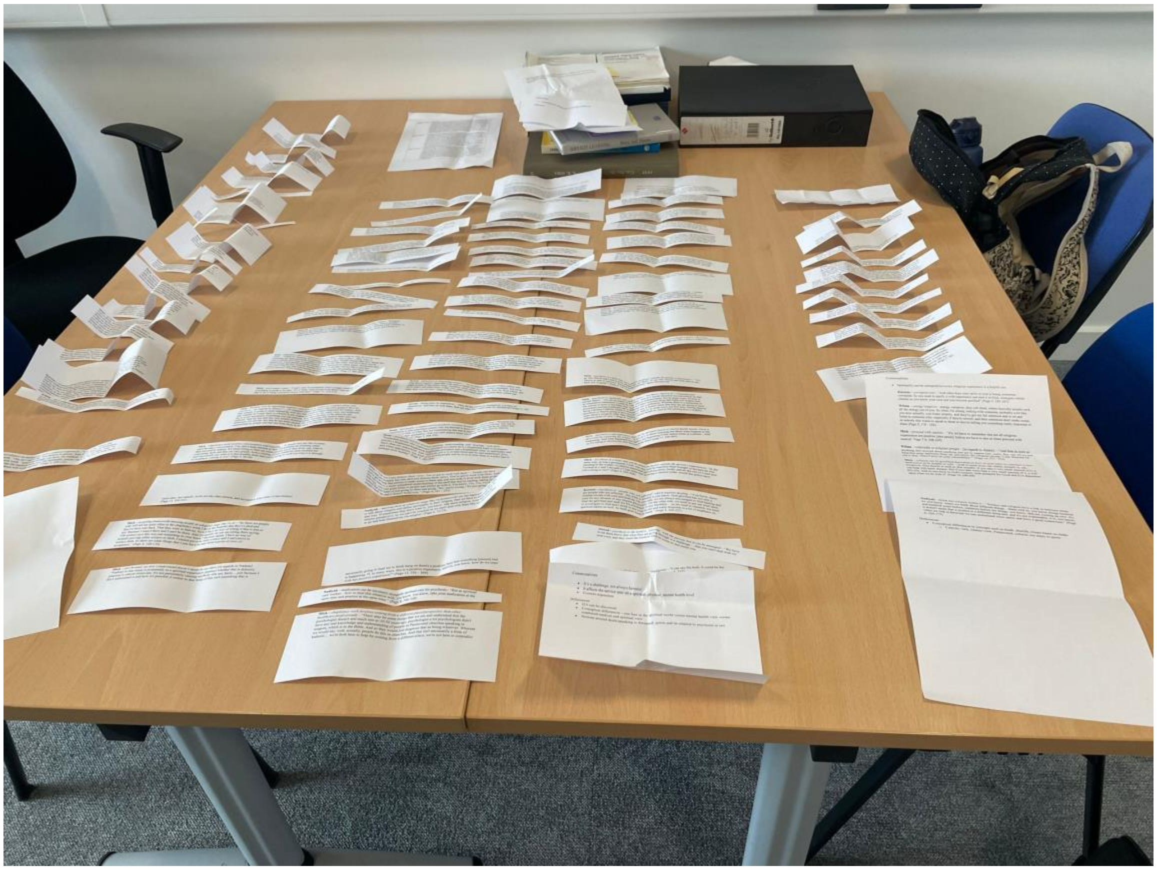
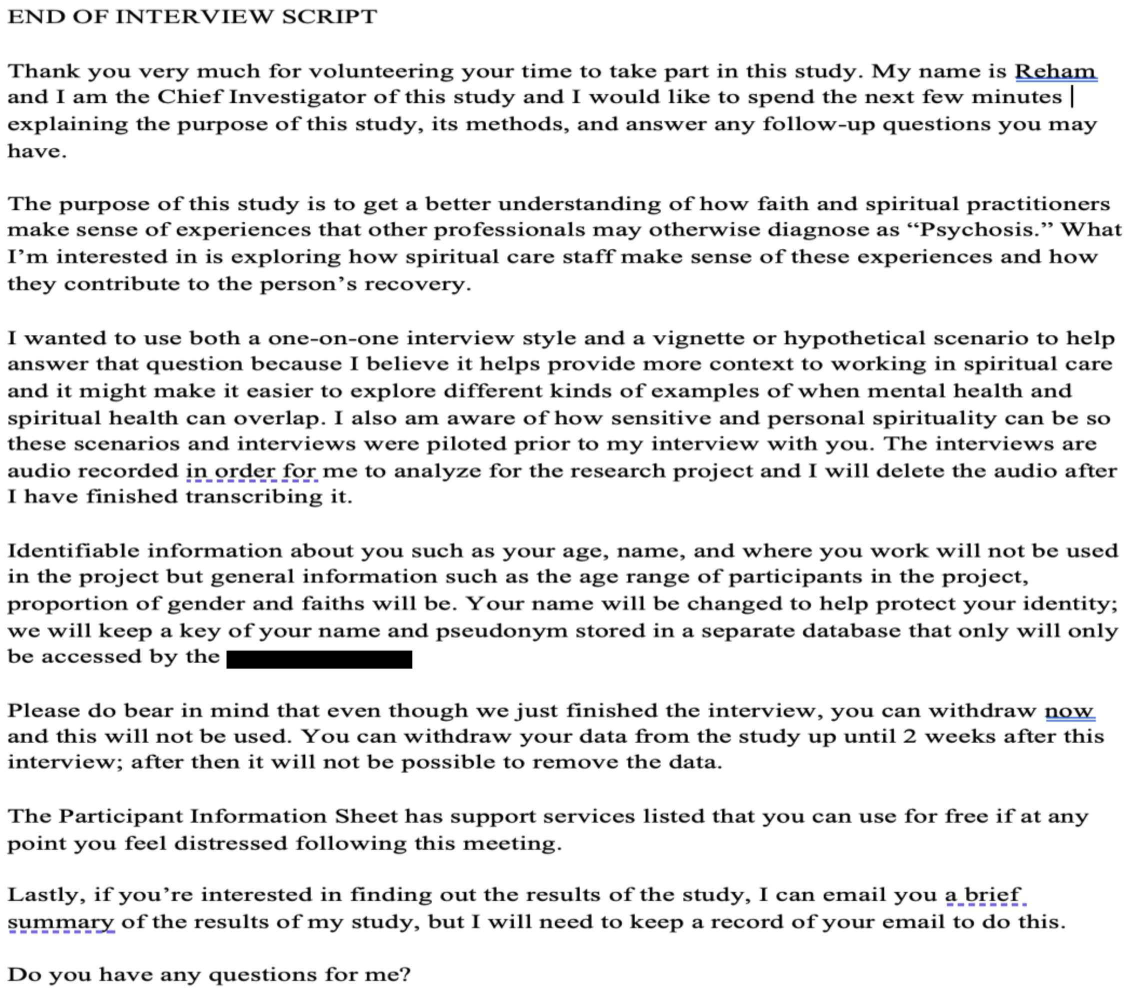
[5] Highlighted in yellow = quotes
Highlight in purple = quotes that are related to another theme/quote from another case
[5] Descriptive comments (written in normal text)
Linguistic comments (written in *italic* text)
Conceptual comments (underlined text)

Appendix N. How themes were physically charted as part of IPA analysis in order to reach clear interpreted themes



Appendix O. Debriefing script used after every interview (Portions redacted to maintain confidentiality and anonymity)



END OF INTERVIEW SCRIPT

Thank you very much for volunteering your time to take part in this study. My name is Reham and I am the Chief Investigator of this study and I would like to spend the next few minutes explaining the purpose of this study, its methods, and answer any follow-up questions you may have.

The purpose of this study is to get a better understanding of how faith and spiritual practitioners make sense of experiences that other professionals may otherwise diagnose as “Psychosis.” What I’m interested in is exploring how spiritual care staff make sense of these experiences and how they contribute to the person’s recovery.

I wanted to use both a one-on-one interview style and a vignette or hypothetical scenario to help answer that question because I believe it helps provide more context to working in spiritual care and it might make it easier to explore different kinds of examples of when mental health and spiritual health can overlap. I also am aware of how sensitive and personal spirituality can be so these scenarios and interviews were piloted prior to my interview with you. The interviews are audio recorded in order for me to analyze for the research project and I will delete the audio after I have finished transcribing it.

Identifiable information about you such as your age, name, and where you work will not be used in the project but general information such as the age range of participants in the project, proportion of gender and faiths will be. Your name will be changed to help protect your identity; we will keep a key of your name and pseudonym stored in a separate database that only will only be accessed by the [redacted]

Please do bear in mind that even though we just finished the interview, you can withdraw now and this will not be used. You can withdraw your data from the study up until 2 weeks after this interview; after then it will not be possible to remove the data.

The Participant Information Sheet has support services listed that you can use for free if at any point you feel distressed following this meeting.

Lastly, if you’re interested in finding out the results of the study, I can email you a brief summary of the results of my study, but I will need to keep a record of your email to do this.

Do you have any questions for me?