An Exploration of the Experience and Sense-Making of Psychosis in a South Asian Population: An Interpretative Phenomenological Analysis.

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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- Acknowledgements -

- Abstract -

There is strong evidence of inequalities in mental healthcare access, experiences and outcomes for service users belonging to Black and Asian Minority Ethnic groups experiencing psychosis. Clinicians and academics have speculated that culture-specific conceptualisations of psychosis, alongside inequitable service provision may explain disparities. There is, however, a dearth in literature exploring this in a South Asian population, despite this ethnic group being the second largest in the UK. The present study aimed to explore how people from this minority group have experienced and made sense of First Episode Psychosis (FEP).

A qualitative approach was used to explore the lived experience and sense-making of British South Asians experiencing FEP and accessing early intervention services. Eight people were interviewed using a semi-structured format. The data were analysed using Interpretative Phenomenological Analysis.

Three superordinate themes were identified in the group analysis: 1) Disconnection from self and others 2) Doubt and dispute 3) Power and shame. Participants characterised psychosis as a terrifying and uninvited intrusion and a fundamental shift in sense of self. Distinctive ethnic, cultural and systemic influence was strongly evident in how people conceptualised their experiences, how they managed their sense-making and where they sought support. Experiences were discussed in the context of power and shame, and this research proposes that socio-cultural/political context and racialised discourses have an impact on self-concept, the experiences of help-seeking (formal and informal), and fundamentally *how* services help them. Implications of this study for practice, policy and research are discussed.

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- List of Abbreviations -

A&E	Accident and Emergency
ACEs	Adverse Childhood Experiences
AESOP	Aetiology and Ethnicity in Schizophrenia and other Psychosis
APA	America Psychiatric Association
BAME	Black and Asian Minority Ethnic
BHS	British Health Survey
BP	British Pakistani
BPS	British Psychological Society
CBTp	Cognitive Behavioural Therapy for Psychosis
CIMH	Cultural Influences of Mental Health Model
CJI	Criminal Justice Involvement
CJS	Criminal Justice Service
CNVs	Copy Number Variants
CRED	Commission on Race and Ethnic Disparities
CRIS-FEP	Clinical Record Interactive Search – First Episode Psychosis
DNA	Deoxyribonucleic acid
DSM	Diagnostic and Statistical Manual
DoH	Department of Health
DUP	Duration of Untreated Psychosis
EI	Early Intervention
EIS	Early Intervention Services
EMDR	Eye Movement Desensitisation and Reprocessing
EMPIRIC	Ethnic Minority Psychiatric Illness Rates in the Community
FEP	First Episode Psychosis
GP	General Practitioner
GWAS	Genome-Wide Associations Studies
HCPs	Healthcare Professionals
HEER	Help from Experts by Experience
HRA	Health Research Authority
IAPT	Improving Access to Psychological Therapies
ICD	International Classification of Diseases
IPA	Interpretative Phenomenological Analysis
IRAS	Integrated Research Application System
ISPS- UK	International Society for Psychological and Social approaches to Psychosis UK
LMICs	Low and Middle Income Countries
MDT	Multidisciplinary Team
MERIT	Metacognitive Reflection and Insight Therapy
MH	Mental health
MHA	Mental Health Act
MHRN	Mental Health Research Network
n	Number of study participants
NHS	National Health Service
NHSx	National Health Service Information Governance

NICE	National Institute for Clinical Excellence
NICE CG	National Institute for Health and Care Excellence Clinical Guidelines
ONS	Office of National Statistics
PIS	Participant Information Sheet
PP	Pakistani individuals residing in Pakistan
PTMF	Power Threat Meaning Framework
PTSD	Post-Traumatic Stress Disorder
REC	Research Ethics Committee
SA	South Asian(s)
SES	Socio-Economic Status
SEMI	Short Explanatory Model Interview
SG	Social Ggrraaacceeesss
UK	United Kingdom
UPSIDES	Using Peer Support in Developing Empowering Mental Health Services
US	United States
WB	White British
WEIRD	Western, Educated, Industrialised, Rich, Democratic
WHO	World Health Organisation

Chapter 1

- Introduction -

There is strong evidence of inequalities in mental healthcare access, experiences of service users and outcomes across different ethnic groups. In 1965, the UK government released the *Immigration from the Commonwealth* White paper (Immigration from the Commonwealth [CMND 2739], 1965), which included specific reference to migrant health. Since its publication, several policy frameworks, for example Delivering Race Equality in Mental Health Care (Department of Health [DoH], 2005) and Race Equality Action Plan (DoH, 2010) have been produced to identify barriers and address disparities in outcomes for Black and Asian Minority Ethnic (BAME) groups. In addition, there are multiple government guidelines that encourage local services to provide "culturally competent" person-centred care for those experiencing mental health (MH) difficulties, including psychosis (NICE CG 178; 2014). However, the translation of government policy into race equity in local services remains an area of contention (Salway et al., 2016).

Epidemiological evidence suggests that rates of psychosis are disproportionately higher in ethnic minority and migrant groups in the UK, particularly those of African-Caribbean and South Asian (SA) heritage (Jongsma et al., 2019; Beattie et al., 2020). Furthermore, there have been reports that people from these ethnic minority groups have different and potentially more difficult pathways into care (Anderson et al., 2014; Morgan et al., 2005), and they are more likely to have a comparatively longer duration of untreated psychosis (DUP), which has been consistently associated with poorer outcomes (Drake et al., 2020; Ran et al., 2015; Marshall et al., 2005).

Some research has proposed that these differences could be due in part to cultural variations in the conceptualisation and explanation of psychosis (Saleem et al., 2019), which may be incongruent with the Eurocentric conceptualisation that currently underpins clinical and academic practice, as well as policy guidelines. However, little research has been conducted in the SA community, despite this population constituting the second largest group in the UK (Office of National Statistics [ONS], 2011). Therefore, the aim of this study is to conduct a qualitative investigation to broadly explore SA participants' lived experience of

first episode psychosis (FEP) and how they make sense of their experiences. It is hoped this study will contribute to the field of transcultural research, inform culturally inclusive service provision and provide direction for future research.

This chapter will present an overview of relevant research to provide the wider context in which this study was conducted. There will be a brief discussion of the epistemological and ontological frameworks within which this study sits, followed by an outline of the terminology used within this field, and some of the key challenges of defining psychosis, ethnicity and culture. Following this, a model of cultural influence on mental health will be introduced, to be used as a reference for the remainder of the chapter. Epidemiological literature detailing the incidence and prevalence of psychosis, patterns of diagnosis and detention in the UK and key factors in the psychosis care pathway will be explored. After which the results of a scoping review, where both national and international literature exploring the experience of psychosis in SA individuals, will be examined. Lastly, there will be a discussion of key discourses in the literature concerning illness beliefs and the impact of the dominance of Eurocentric models in research, intervention and recovery.

A constructivist epistemological position

As this study is exploring sense-making, there is a particular focus on how psychosis is conceptualised and the impact of the current prevailing discourses concerning the perception of experiences. Therefore, the overall design of the study and the research aims are informed by a social constructivist model (Gergen, 1977), which allows for a degree of theoretical flexibility when considering the following:

- how language impacts the construction of reality.
- the existence of a complex interplay between reality, power and language.
- the conceptualisation of the nature of truth and reality, including how people and groups can inform the construction of their perceived reality.
- how social phenomena are formed, institutionalised and traditionalised.

Within this framework, one understanding is that truth is a socially constructed concept, and therefore many truths exist, rather than one ultimate truth. Thus, reality is considered not be fixed, but dynamic and flexible and something that can change with the knowledge

and interpretation of it. Regarding the concept of psychosis, Higgins and Leibowitz (2002) suggest that from a social constructionist perspective, the prevalent discourse is the deficit model, which can potentially serve to overshadow the holistic experience.

> "*The many co-constructed spaces from which to see and respond to psychosis – culturally, relationally, psychologically and neurologically – may be multiple facets of the same reality*" (Putnam, 2019)

Exploring how psychosis is perceived and understood from multiple perspectives, including first-hand (i.e. those who have experienced psychosis), and observer perspectives (i.e. the clinical and academic community who are working with people who experience psychosis), has several important implications. It will help us understand congruence and incongruence between these perspectives, for example, regarding what individuals believe they are living with or recovering from, what adjustment to psychosis involved for them, the concept of intervening and the role of services, and the construct of insight in psychosis.

All of these can help inform our understanding of the development (including risk factors) and maintenance of psychosis and has important implications for help-seeking and engagement with services. One way to begin to unpick individual understanding is to explore sense-making and attend to the nature and context of the experiences that cause the distress, how the distress was and is experienced and how it is understood, and how it informed the individual's decision-making. In addition, the current study could help us understand the limits of current thinking and inform the ways in which our thinking can develop, with a move towards the decolonisation of MH (Lucero, 2011; Hernández-Wolfe, 2011). Decolonisation of MH in its broadest sense refers to equity of resources, equalising power and privilege and challenging the assumptions institutions are based on (Fay, 2018).

A brief reflection on terminology

Categorisation and classification have been inevitable aspects of attempts to understand how people conceptualise their experiences and the world (Bowker & Star, 1999). The

conceptualisation of 'psychosis'[1] has been a source of longstanding debate. Classification of mental illness into discrete categories or 'symptoms' has led to a trend of a 'single-symptom' approach to research, for example, exploring specific experiences such as hallucinations and delusions. At the same time, attempts to capture broader experiences via umbrella terms have led to a great deal of variation in terminology across academia and clinical practice, for example, psychosis, and more recently 'unusual experiences' or 'perceptual anomalies'. Although there is a degree of overlap, these concepts can be considered separate and each hold their own set of connotations. In the introduction and discussion sections of this thesis, terminology is used in line with that of the authors cited. In reporting the results of this study, effort was made to use the participants' own terminology for their experiences. For the purposes of pragmatism, given the term psychosis is used across many systems, it will be used in all other cases. Nevertheless, this study is deconstructing this phenomenon, and therefore, importantly, it is not about people who *have* psychosis, but about the experiences of people who have *received* a diagnosis of psychosis.

Defining psychosis

Currently, the two most widely used classification systems are the International Classification of Diseases 10th Revision (ICD-10: World Health Organisation [WHO], 2016) and the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5: American Psychiatric Association [APA], 2013). There are differences across the two diagnostic systems, related to classification and other specifications, such as duration of illness (Valle, 2020). However, both refer to diagnostic categories, within which both specify 'positive symptoms'. Referencing hallucinations, defined as a sensory perception in the absence of external or somatic stimuli, such as hearing voices in the absence of an external stimulus. Or delusions, defined as fixed false beliefs. They also include reference to formal thought disorder and 'negative symptoms', such as apathy or emotional blunting, or psychomotor

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[1] After I have defined contested terms, they will no longer be presented in inverted commas.

symptoms such as catatonia. These can also be accompanied by affective symptoms, such as depression and anxiety, and other difficulties such as poor attention and concentration.

The challenges associated with classification in MH are widely reported (Parnas, 2015), and their use continues to be debated, not least regarding their cultural sensitivity, diagnostic reliability (e.g. inter-rater of some categories), ecological reliability and/or validity, issues surrounding comorbidity (i.e. shared signs/symptoms) and their overall clinical utility, to name a few. Parnas (2015) outlines the paradox that exists when using classification systems, in that they are both complex diagnostic frameworks that also risk simplifying multifaceted psychopathological experiences into homogenous factors and phenomenological primitives. There has been a gradual shift in different countries to redefine terminology. For example, Japan has recently redefined "schizophrenia" as "togo shitchosho," translated as "integration disorder" (Choudry & Farooq, 2018). Shifts in conceptualisation alongside the complexity of classification means that operationalising psychosis will continue to be an ongoing consideration.

More recent iterations (ICD-11: WHO, 2019) have attempted to include broader conceptualisations, including the adoption of a lifespan approach, and culture related information and guidance to increase clinical utility (Reed et al., 2019). DSM-5 (APA, 2013) distinguishes between normal religious and spiritual experiences, religious and spiritual problems leading to mental disturbance and mental disturbances with a religious and spiritual context. Along with attempting to account for cultural variation in the description of disorders, it also includes guidelines for cultural formulation, including cultural identity, cultural conceptualisation of distress, and cultural features of the relationships with healthcare professionals (HCPs). However, as with the general use of classification systems, the clinical utility of these subgroups and adoption of the formulation guidelines remains a challenge.

The idiosyncratic nature of psychosis means identifying a single definition is problematic in and of itself, and may serve to undermine the complexity of such an experience and its underlying roots, such as the impact of social power and position in society. Continuing to rely on a diagnostic/medical Eurocentric model of MH difficulties risks decontextualizing the individual (Langa & Gone, 2020). Furthermore, the dominant use of clinical and

scientific/medical language to conceptualise psychosis risks disregarding the culture-specific lived experience and associated language of these phenomena (Bergström et al., 2019). Including neglecting the role of systemic or environmental factors, such as the iatrogenic effects of treatment, as well as the central role of trauma (Read et al., 2009). Critical to this debate is that the predominant definition is culture specific, for example, the conceptualisations outlined under WHO and APA are internationally prevalent (Reed et al., 2019), and based on a Eurocentric medical model.

In response to this debate, other perspectives and models have been proposed such as the continuum perspective (DeRosse & Karlsgodt, 2015) and psychosocial definitions such as the power threat meaning framework ([PTMF] Johnston & Boyle, 2018) and the Recovery model for psychosis (Leonhardt et al., 2020). The continuum model suggests that psychosis lies on a spectrum, acknowledging that there is variation in the level of distress or impact on quality of life in people's experiences. PTMF and the Recovery model proposes that psychosis is a response to adverse environments and trauma, acknowledging cultural, relational, social and biological contexts.

Based on their phenomenological work, Sass and Parnas (2003) proposed the Ipseity-disturbance model which proposes that a disturbance of, or instability in, basic or minimal sense of self (ipseity) contributes to the central disturbances involved in schizophrenia. Under this framework, ipseity refers to the fundamental sense of self-hood (the "me-ness") that makes up the self-experience. This core change in the "me-ness" rather than delusions or hallucinations accounts for the lived experience.

Nonetheless, it can be argued, these models (perhaps with the exception of the Recovery model) continue to reinforce existing hierarchies, whereby they are imposed professional models, with limited acknowledgement of those with lived experience providing their own explanations (British Psychological Society [BPS], 2018).

In this study, 'first episode psychosis' will be understood as the first time an individual experiences psychosis and presents to statutory services (Norman & Walla, 2001; Breitborde et al., 2009). In the UK, Early Intervention Services for Psychosis (EIS) have been implemented to meet the needs of this population. A standard EIS consists of a

multidisciplinary team offering psychological therapy (CBTp), family/carer support, physical health/lifestyle support, pharmacological intervention/management, support with education, employment and training and crisis care. However, there is significant variation in EIS provision across the UK (Neale & Kinnair, 2017). Currently, there are three service models operating in the UK: a 'stand-alone' model working independently of Community Mental Health Teams (CMHTs), an 'integrated' model, working entirely within an CMHT and a 'hub and spoke' model. The EIS utilised in this study consists of a 'hub and spoke' model, where there is an EIS 'hub' providing access to specialist support which is based within a CMHT. This service offers up to a three year pathway, with a treatment model that includes psychological, pharmacological and social support.

Defining ethnicity

According to the British Health Survey (BHS: NHS Digital, 2017) there are four broad ethnic groups; Black-African, African-Caribbean, Asian and White in the UK. Asian (7.5%) and Black-African/African-Caribbean (3.3%) are the two largest ethnic minority groups in the UK after White (86.0%) (ONS, 2011). Defining ethnicity is difficult and there are several methodological and conceptual debates within this field (Okazaki & Sue, 1995) that would question the ethnic groups identified by the BHS.

'Ethnicity', 'ethnic group' or 'ethnic identity' are descriptive terms that are often used interchangeably. They may be used for identification by others and for individuals to self-identify. However, there is currently no generally agreed definition, and whether one can truly unpack ethnicity is a source of much debate. Fernando (2012) proposes that ethnicity is an umbrella term that encompasses race (or physical appearance) and culture (one's social similarity). Alongside this ethnicity can also reflect one's own awareness of group belonging, and how this group is perceived by society. Although ethnicity is often used interchangeably with race and culture, these are separate constructs that are intertwined. In this study, race is also considered in the context of power, dominance and subjugation.

However, as noted earlier, as with any classification system, it is an ongoing challenge to truly identify meaningful ethnic minority categories, without reducing and oversimplifying an identity. Okazaki and Sue (1995) conclude that although there appears to be a move

towards a multidimensional rather than categorical construction of ethnicity and culture, this brings along its own set of challenges when conducting research.

The Indian subcontinent of southern Asia is comprised of the following: Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan and Sri Lanka. In the UK approximately 5.2% of the total population identified as 'South Asian' (ONS, 2011). Ongoing immigration has led to Pakistan and India being amongst the top three most common countries of origin for UK migrants in 2019 (Rienzo & Vargas-Silva, 2020). Given that these communities represent a large population in the UK, and for continuity and comparison across research, this study will use the term South Asian to pertain to the following countries: Bangladesh, India and Pakistan. However, there is a category fallacy in the term South Asian, in that it does not constitute a homogenous group of people: there is a very high degree of religious, linguistic, cultural and economic heterogeneity in this population.

In a similar vein, the term 'culture' also carries a risk of stereotyping and homogenising a group of highly diverse people. Corin et al. (2005) suggests that it is a misconception to assume people are passive recipients of culture, and mobility exposes individuals to a variety of cultures that are actively engaged with. It is important to acknowledge that culture is a fluid concept and not static. It is influenced by surrounding cultures, and is not the only salient framework by which people define themselves. Belonging to a culture does not necessarily mean you are a part of a single coherent homogenous group e.g. "Indian culture". The aim of this study is to explore how the societal and cultural context reflect or modify the lived experience and meaning-making of people experiencing psychosis.

Exploring cultural influences on mental health

Taking into account the cultural context and social positions of service users is an important part of making sense of their experiences and developing culturally relevant interventions. Figure 1 illustrates the cultural influences on mental health (CIMH) model (Hwang et al., 2008). This model will be used as a framework to discuss SA cultural factors in the context of the experience of psychosis.
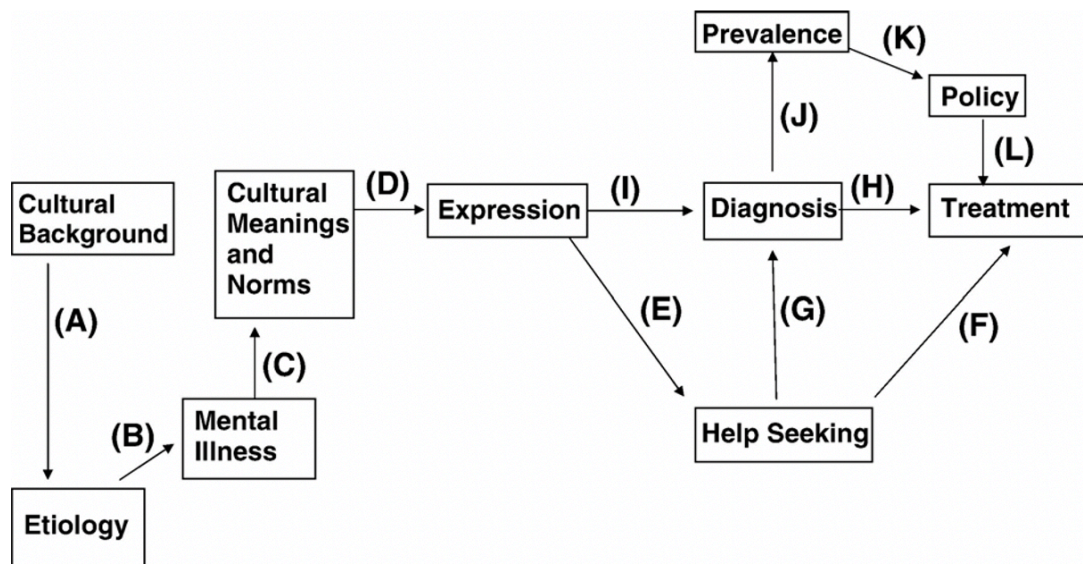
Figure 1. The Cultural Influences on Mental Health (CIMH) Model.

Before exploring the impact of cultural meanings and norms regarding MH, it is important to acknowledge distinctions and overlap that exist between cultural beliefs and religious beliefs. Abdulla (2018) describes culture as operating on two levels, expressive forms (music, arts, heritage and cultural places) and ideas and beliefs systems, values and norms that govern social behaviour. Religious beliefs and spirituality are defined as relating to beliefs and behaviours about spiritual reality, God, morality, purpose and the communication of these (Loewenthal & Lewis, 2011). Abdulla (2018) notes the challenges of distinguishing between these two concepts, and how cultural practices have become "religionized" and religious ideas and spaces have become a part of culture.

Aetiology of psychosis

The aetiology of psychosis has been explored from several perspectives. Biomedically, psychosis has been associated with neurochemical differences (e.g. in glutamate, dopamine and serotonin) (Kesby et al., 2018), neuroanatomical changes (e.g. in grey matter volume) (Fusar-Poli et al., 2012) and familal and molecular genetics, such as genome wide association studies (GWAS) and studies of chromosomal variants, particularly copy number variants (CNVs) (Cardno & Owen, 2014). However, this research can be methodologically limited (e.g. heterogeneity of diagnoses, study samples, instruments, medication, disentangling environmental interactions etc.).

Other perspectives include cognitive understandings, such as cognitive behavioural (Birchwood & Chadwick, 1997; Paulik, 2012; Ritsher et al., 2004), or psychodynamic (Romme & Escher, 1989) models of voice hearing. Although these models offer a valuable insight into potential processes underpinning psychosis, a focus on single symptoms overlooks the broader factors that may underpin this phenomenon. For example, culture, deprivation, family circumstances, urbanicity, inequality and discrimination are also factors associated with the aetiology of psychosis (Kirkbride et al., 2012).

Psychological and social perspectives have also demonstrated the impact of adverse childhood events (ACEs) and the cumulative effect of trauma and post-traumatic stress disorder (PTSD) in psychotic aetiology (Schafer & Fisher, 2011; Fisher et al., 2010; Sar et al., 2010). A seminal meta-analysis reported that exposure to traumatic experiences during childhood increased risk of developing psychosis by 2.72 times (Varese et al., 2012) and this has been substantiated by qualitative findings (Longden et al., 2016). It appears that there is increased prevalence of ACEs in ethnic minorities experiencing psychosis (Levit et al., 2021; Berg et al., 2015). However, this research is often methodologically limited by variations in definitions of ethnicity and poor stratification of ethnic groups to allow for cross-comparison and generalisation. One must also consider cultural variations in the definition of trauma and psychopathology and how it is operationalised in research.

It is likely that psychosis arises from a complex interaction. For example, the stress-vulnerability model (Zubin & Spring, 1977), proposes that there are individual differences in vulnerability to the development of psychosis, based on biological, psychological and social factors that interact with the presence of external stressors. Alternatively, there is literature suggesting that discrimination and stress-exposure rather than stress-vulnerability may account for racial health disparities (Sternthal et al., 2011). More recent epigenetic research proposes that environmental stress can have an effect on gene expression which can in turn impact the development of psychosis (Pai et al., 2019). Tahira and Agius (2012) and Mirza et al. (2019) propose that increased acculturative stress associated with holding and reconciling two cultures (Berry, 2005), that of the host country and the culture of one's parents may explain findings suggesting increased rates of schizophrenia in 2nd generation migrants (Cantor-Graae & Selten, 2005). However, much more methodologically sound research is required to substantiate these initial claims.

Incidence and prevalence of psychotic disorders in BAME groups

Estimates of the incidence and prevalence of psychotic disorders vary across different populations, geography and social characteristics. In the UK, there is an approximate life-time prevalence of 0.7% (McManus et al., 2016). In South Asia, there is an approximate life-time prevalence of between 0.2 – 0.4% (Hossain et al., 2020). An increase in risk of psychosis has been reported in men (Jongsma et al., 2019), and the average age of onset is considered to be mid- to late- twenties, but with wide variation across studies (Kirkbride et al., 2012). Higher rates of psychosis have been reported in BAME groups in particular. In a large-scale UK study (AESOP) very high incident risk ratios were found in both African-Caribbean (9.1) and Black African (5.8) individuals, with modestly raised risk in the Asian population (1.4) (Fearon et al., 2006). However, there is a large degree of heterogeneity in rates due to methodological design (e.g. nomenclature, first contact vs. registry-based designs) and limited geographical spread and small sample sizes. This should be considered in the interpretation of findings.

The relative risk has been reported to be particularly high in migrants from low and middle income countries (LMICs) to the UK and other higher income countries (Cantor-Graae & Selten, 2005), and this appears to be a fairly consistent finding (Jongsma et al., 2019; Bourque et al., 2011; Fearon & Morgan, 2006). Some epidemiologically studies have suggested marginally increased incidence rates in SA, particularly those of Pakistani and Bangladeshi heritage compared to White majority groups, but not compared to Black ethnic minority groups (Kirkbride et al., 2017; 2012; Saleem et al., 2019). This is consistent with a more recent study exploring FEP incidence rates (per 100,000 person-years) in the UK (McDonald et al., 2021), which also reported increased rates in Bangladeshi (39.08) and Pakistani (33.58) individuals compared to White other (21.46) and White British (19.52) groups. Interestingly, the incidence rate appeared relatively lower in people of Indian ethnicity (13.58) compared to all the other ethnic groups included in this study. Suggesting differences between and within ethnic minority populations.

Recently, Beattie et al. (2020) reported a significantly higher risk of psychosis in Pakistani individuals and a trend for higher risk in Bangladeshi individuals, compared to the indigenous White population in the Bradford area of West Yorkshire. The Indian community,

conversely, were reported to have a relatively lower risk. There was a higher risk for those in the age band of 25-35 compared to younger ages, for Pakistani and Bangladeshi individuals, which suggests a late presentation for treatment to EIS. The authors conclude that their findings are consistent with anecdotal reports that SA service users access informal support initially, such as traditional faith healers (Shah et al., 2019), and this may explain the difference in age at presentation to services. It is also possible that variation in age of entry could be due to differences in patients' and their families conceptualisation of experiences and help-seeking behaviours. Further methodologically rigorous, epidemiological research is needed to replicate these initial findings in a larger sample and identify differences within SA groups.

Epidemiologists have speculated on the migratory process, under reporting of psychosis, and use of indigenous treatments prior to specialist care as further factors related to variation in rates (Beattie et al., 2020; Saleem et al., 2019; Dutta et al., 2019). An argument can be made that epidemiological research alone might not be best placed to investigate this. Given the variation in rates of psychosis across communities that experience migration, problems with cultural assimilation and sociodemographic disadvantage; qualitative exploration will help explore relevant processes, including potential protective factors within this group.

Pinto et al. (2008) proposes that the increase in prevalence in BAME groups could be due to misdiagnosis in this population via clinician bias and cultural relativity. Clinician bias for example, via cultural stereotyping and institutional racism may inflate the true incidence. Cultural relativity argues that diagnostic differences are due to ethnic variations in symptom expression. For example, Hickling et al. (1999) reported an increase in diagnosis when using a structured assessment tool versus unstructured clinical diagnosis that places symptoms in a cultural context. However, this is yet to be replicated across different ethnic groups. Diagnostic differences could also be due to application of a Eurocentric biomedical model to non-Western cultural beliefs. Clinician bias and cultural relativity may both effect the way services reach ethnic minority groups, and how minorities in turn engage with services.

Key factors in the psychosis care pathway

Duration of untreated psychosis

Research concerning average delay in untreated psychosis is variable and subject to the same limitations of epidemiological research within this population. A 'short DUP' is commonly defined and operationalised as ≤ 6 months and a 'long DUP' as ≥ 6 months (Drake et al., 2000). Dependant on the methodology, definition of DUP and outcomes, there have been reports of mean delays of between 9 to 53.1 weeks in adults (Brunet et al., 2007). There is robust evidence to suggest a delay in identifying and seeking support following the onset of psychosis is correlated with illness duration, loss of social and occupational function, risk of mortality and increase in treatment resistance (Albert et al., 2017). These findings have been replicated in an ultralong study (Ichinose et al., 2010), FEP (Marshall et al., 2005) and SA samples, where increased DUP was positively correlated with poorer somatic and functional outcome (Thirthalli et al., 2011), poorer treatment response (Srinivasan et al., 2004) and increased mortality (Ran et al., 2015).

However, epidemiological research exploring length of DUP across different ethnic groups has been equivocal. One study reported a shorter DUP amongst Asian service users compared to White British (60 days vs 113 days, respectively) (Ghali et al., 2013). However, this have not been consistently replicated, and other research has demonstrated no significant group differences in DUP (Iyer et al., 2010), even when accounting for culturally mediated illness attributions (Singh et al., 2015). Although, Oduola et al. (2020) report a trend for shorter DUP in their Asian sample, differences between groups did not reach statistical significance. Methodological limitations of how DUP is measured and ethnicity is defined, limits the applicability of these reports.

There have been speculations that observed similarities in DUP could be due to minority groups accessing both formal and informal intervention simultaneously (Singh et al., 2015; Islam et al., 2015). Whereas observed differences could be related to "double-stigma" experienced by ethnic minorities accessing formal intervention (Gary, 2005) and adverse care pathways or negative service experiences, creating a vicious cycle of fear that acts as a barrier to formal help-seeking (Degnan et al., 2018). It can be argued here that poor cultural

awareness and adaption serves to add to this cycle. This study may help address these speculations, by exploring the lived experience of FEP, including help-seeking pathways.

Pathways to care

There is substantial evidence to suggest that ethnic minorities have a more complex and less desirable route to psychiatric care and that they are more likely to be detained under the Mental Health Act 1983 (amended, most recently by the Mental Health Act [MHA] 2007) (DoH, 2008) than White patients (Bahl, 1999). In their recent review, Barnett et al. (2019) reported that 'BAME groups' were more likely to have compulsory admissions to hospital compared to White ethnic groups, with Black groups also at highest risk of readmission. Of the two studies that specifically looked at the SA ethnic group, results were not significant. Overall, they found that UK studies reported significantly increased odds ratios compared to international studies, and migrant groups were more likely to be compulsory admitted compared to host nation populations. The authors propose that "untested explanations" perpetuated in the literature such as lifestyle, cultural health beliefs, clinical characteristics and demographic-bound assumptions of minority ethnic groups may explain results.

Unfortunately, this also appears to be the case for EIS experiences in the UK (Mann et al., 2014; Oduola et al., 2019). Oduola et al. (2019) compared compulsory admission rates across two population-based studies (CRIS-FEP and AESOP) in FEP and reported Black-African and Black-Caribbean individuals remain three times more likely to be compulsorily admitted compared to White British individuals. No data for other ethnic minority groups were available in this report. Disturbingly, the authors found that there was a 'triple disadvantage' if the service user was female, from an ethnic minority and experiencing a MH illness, especially for Black-British and Black-African women who were ten times and eight times, respectively, more like to be admitted to hospital, than White British women. The authors suggest that institutional racism, difference in illness expressions and variation in explanatory illness models create a more adverse pathway into care.

Service engagement

Research has suggested that in general, people from ethnic minorities are less likely to receive MH services than the majority population (De Haan et al., 2013). South Asian

individuals are less likely to be referred (Burman et al., 2002), to be recognised as experiencing MH difficulties when they present to their general practitioner (GP) (Commander et al., 1999), to utilise MH services generally (Baker, 2020; Kapadia et al., 2018) and for psychosis (McManus et al., 2016) compared to the general population in the UK. Recently, Mirza et al. (2019) found that White British individuals were more likely to report experience with MH compared to SA, indicated by reporting more contact with MH services and more contact with people with MH problems. Mirza and colleagues note that in the UK, 1st and 2nd generation SA are 30% less likely than average to access NHS MH services (inc. IAPT[2]), compared to White British who are 3% more likely than average to make contact.

In terms of engagement with EIS, research indicates that SA service users are more likely to miss outpatient appointments and be 'non-compliant' with medication, with this being most prevalent in those of Bangladeshi ethnic origin in this sample (Agius et al., 2010). Others have reported 1st generation immigrants had fewer primary care contacts during the six months prior to their diagnosis of psychosis, compared to the general population (Kline & Thomas, 2018) and that 1st and 2nd generation immigrants experiencing FEP are three times more likely to demonstrate treatment attrition than non-immigrants (Quellet-Plamondon et al., 2015). Several explanations have been offered, including inadequacy of NHS services in addressing religious, cultural and language needs (Chew-Graham et al., 2002), differences in help-seeking behaviours (Kirmayer & Bhugra, 2009) and clinicians holding cultural stereotypes leading to under referral (Kapadia et al., 2018).

Two recent systemic reviews have collated help-seeking experiences of Asian MH service users. De Haan et al. (2018) reported higher drop-out rates in this group, and this was associated with poor therapeutic alliance. This appeared to be mediated by ethnic matching of therapist and service user. However, results did not appear to be consistent across studies, and there were methodological variations (definitions of 'SES', 'Asian' and

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[2] Improving Access to Psychological Therapies is a primary care service especially created to provide accessible psychological therapies primarily for those experiencing low mood and anxiety.

'disorder') which need to be considered in its interpretation. Furthermore, only two studies were conducted in the UK, with the majority in the US, which has a different health care system, further limiting generalisability. Prajapati and Liebling (2021) reviewed a more homogenous set of studies, all conducted in the UK, and reported overall themes of SA MH service users feeling distanced from services, experiencing dilemmas of trust and a threat to cultural identity. Prajapati and Liebling conclude that further research into the lived experience of MH in this population is urgently required.

Rates of recovery

Up to one third of individuals experiencing psychosis, who have accessed services, 'recover', are considered in remission, or are no longer distressed by psychotic symptoms and are able to function in society (Bertelsen et al., 2008). Findings regarding recovery from psychosis, internationally and across ethnic groups, have been equivocal. In their historic prospective study, Harrison et al. (2001) reported epidemiological findings from the International Study of Schizophrenia, at 15- and 25-year follow-up. In a sub-analysis, centres in Nottingham, UK and Chandigarh, India had better outcomes than other centres. However, earlier work looking at the same data set, in a sub-analysis on the "developing" group consisting of centres in India (Madras, Chennai and Chandigarh) reported relatively poorer outcomes compared to their "developed" counterparts (Hopper & Wanderling, 2000). Results from this data set should therefore be interpreted with caution due to poor data quality control and inconsistency in reports. Additionally, there are methodological concerns regarding baseline diagnosis, heterogeneity in definitions of recovery, selective outcome measures and attrition rates. In a more recent meta-analysis of FEP patients, remission rates were significantly higher in studies from Africa, Asia and North America, compared to other regions, including Europe. Recovery rates were highest in North America compared to Europe and Asia. Interestingly, higher rates of recovery were moderated by White ethnicity, and lower rates of recovery was moderated by Asian ethnicity (Lally et al., 2017).

Overall, the limited number of large-scale studies and methodological concerns make it difficult to make any substantive claims about rates of recovery nationally and internationally. Currently, there are no robust data on recovery rates in those from the SA community residing in South Asia compared to those who have emigrated to the UK.

Exploring lived experience of psychosis

Exploring the lived experience of psychosis is an expanding field of research. Within the growing literature, first person accounts have provided increasing knowledge of the concept of psychosis, beliefs about the factors that contribute to its presence and in some cases persistence. The seminal meta-synthesis conducted by McCarthy-Jones et al. (2013) identified how people experienced psychosis (e.g. loss, rebuilding lives and hope), made sense of these experiences (e.g. biomedical and/or spiritual explanations) and perceived contributory factors (e.g. ACEs, trauma, iatrogenic effects of intervention). However, a notable limitation in the context of the current study is that all studies were restricted to Western European and North American populations and there was limited representation from different ethnic minority groups across the 97 studies included for synthesis.

More recently, Hansen et al. (2018) conducted a meta-synthesis of the experience of psychosis in those accessing EIS. Themes of feeling 'something is wrong and confusion', 'loss of autonomy', 'recovery and reconnecting' and 'stigma and vulnerability' were identified across studies. A strength of this synthesis is its attempt to capture first person experience of FEP. However, as with the previous synthesis, these first-person narratives were described predominantly by White individuals, thus limited in capturing cultural specific issues and differences. Interestingly, although the authors suggest various other ethnicities were represented, this information was not readily available. Furthermore, and as noted by the authors, this synthesis was conducted by White, middle-class individuals positioned within the MH care system and therefore this orientation alongside being situated in a Western culture may have impacted interpretations and what was identified as salient.

Interpretative Phenomenological Analysis (IPA) investigations of the lived experience of psychosis and have identified several key findings. For example, the role of the voice(s) and the relationship with the voice(s) (Rácz et al., 2017). Similarly, Mawson et al. (2011) identified themes related to the voice(s) identity, the impact of voice hearing on sense of self, control and voice hearing and the impact of voice hearing on interpersonal relationships. In an investigation of the experience of delusions (Todd et al., 2009) participant's described feeling fearful, experiencing a sense of uncertainty and loss and adjustment to experiences. In studies looking at broader experiences of psychosis, using

IPA, themes of external and internal stigma (Knight et al., 2003), trauma of acute FEP experiences (Dunkley et al., 2013) and self-criticism and self-compassion (Waite et al., 2015) have been reported. As with the wider literature in this field, these studies are limited by exploring experiences of White service users (Mawson et al., 2011), using heterogenous mixed-ethnicity samples (Waite et al., 2015), a single symptom approach and a heterogenous nomenclature of psychosis (Rácz et al., 2017; Todd et al., 2015).

Lived experience of psychosis in SA community: A scoping review

A scoping review to identify research exploring the lived experience of psychosis for SA individuals identified 13 studies. Six were cross-sectional studies conducted in South Asia (Shah et al., 2019; Naeem et al., 2016a; Saravanan et al., 2008; Corin et al., 2005; Tirupati & Thara, 2001; Ahmad et al., 2017). Three were cross-comparative studies, of which one was across South Asia and Canada (Iyer et al., 2010), one across South Asia, US and Ghana (Luhrmann et al., 2015) and one across South Asia and the UK (Suhail & Cochrane, 2002). Lastly, four studies explored the experiences of SA migrants (1st and/or 2nd generation). One study was conducted in Canada (Virdee et al., 2017). Three studies were conducted in the UK (Connor et al., 2016; Dein & Sembhi, 2001; Weatherhead & Daiches, 2010), all using heterogenous SA samples.

Four of the five cross-sectional studies conducted in South Asia explored service user and family member illness beliefs. Reports suggested people held one predominant belief (e.g. psychosocial stress) (Tirupati & Thara, 2001) or a combination of psychosocial stress, spiritual or religious illness beliefs (such as magico-religious influences, Jinns[3] and black magic) (Shah et al., 2019; Naeem et al., 2016a; Saravanan et al., 2008). Illness beliefs appeared to impact the type of help sought, and studies reported service users using non-medical healers (Naeem et al., 2016a), temple healing and prayers (Saravanan et al., 2008) and traditional healing practices before, during and after formal service intervention (Shah et al., 2019). Shah et al. (2019) suggested stigma was evident in the use of the term "pagal" (loosely translated as "crazy") which family members used to describe service users. This

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[3] In Islamic belief Jinns are described as supernatural creatures.

was echoed in Saravanan et al's (2008) report of the general public perceptions of psychosis characterised as loss of control, being lazier and more uninhibited.

Corin et al's (2005) primary focus was on comparison of experiences and understanding between female service users diagnosed with schizophrenia and family members. The authors noted convergence across accounts regarding symptom descriptions, social isolation, increased aggression, withdrawal and across illness beliefs (evil spirits and black magic). Divergence was noted in level of support provided by different family members (parental vs. in-laws).

However, several limitations should be considered in the interpretations of these findings. Some studies had a heterogenous sample (Shah et al., 2019; Naeem et al., 2016a; Corin et al., 2005; Tirupati & Thara, 2001) e.g. diagnosis, duration of experiences and length of time in services (which may have impacted exposure to different conceptualisations) and integrating service user and family perspectives. In addition, Saravanan et al. (2008) used case vignettes (which may have prompted people to think in a certain way) and both this study and Naeem et al's (2016a) lacked multiple coders for their qualitative analysis.

Ahmad et al. (2017) reported that seeking alternative treatment (e.g. traditional faith healer), 'lack of insight', poor economic status and using psychoactive substances as an alternative or consequence of illness were associated with treatment non-adherence and relapse in their sample. The authors suggest that engagement in traditional healing approaches for spiritual explanations of MH illness such as "Jinn", "Peeri/faqeer" and "Ta'wiz" are prevalent in Pakistan. However, other potential factors may have contributed to relapse and the study is limited by no control group for comparison.

Overall, in these studies the focus appeared to be specifically on illness beliefs and help-seeking, and there remains a gap in the literature exploring the broad experience of psychosis in SA individuals. There are some specific cultural issues that require further exploration in this group, such as internalised stigma for service users, pluralistic explanatory models and underlying reasons for help-seeking choices.

One multi-site study explored outcomes and experiences in a FEP sample across Chennai, India and Montreal, Canada (Iyer et al., 2010). Iyer et al. (2010) identified no differences in

DUP, but a significant difference in age of entry into services, 29.26 vs. 22.74 years old, respectively. Higher family involvement was observed in the Chennai sample, and this sample showed greater improvement in negative symptoms and social and occupational functioning after one year. No differences were observed in outcomes for positive symptoms between both groups. Findings suggest there are differences in age of entry between groups and there is an impact of sociocultural context on intervention and outcomes in FEP. However, variation may also be due to differences in mental health systems (inc. referral pathways) and assessment methods between countries. Some research has suggested social development stage and age of onset are associated with outcome and attrition rates (Häfner et al., 1999). A qualitative exploration of FEP has potential to extend and introduce further insight, for example, regarding potential protective factors in this group such as family involvement.

Luhrmann and colleagues conducted a single-symptom qualitative study, exploring the experience of voice hearing in service users across San Mateo, US, Chennai, India and Accra, Ghana (Luhrmann et al., 2015). All three groups reported hearing good and bad voices, conversing with the voices and positive and negative appraisal of experiences. However, those residing in Chennai and Accra reported better quality relationships with their voices, compared to the San Mateo sample who characterised voices as markedly more "harsh and violent". Furthermore, the San Mateo sample attributed voices to "brain disease" compared to Chennai and Accra sample who described spiritual or magical beliefs. This research suggests there are important difference between how Western and non-Western individuals experience and interpret psychosis experiences. The authors suggest that this may be due to the former groups being more comfortable interpreting voices as another relationship in their world, and not a sign of a violated mind. Whilst this methodology offers value, it risks reducing the experience of a multifaceted phenomenon. Where there is a dearth in literature, there is perhaps value in exploring the experience of psychosis in its broadest sense.

Suhail and Cochrane (2002) explored the effects of culture and environment on the phenomenology of delusions and hallucinations, in three cohorts: British Pakistani (BP, n=53), Pakistani individuals residing in Pakistan (PP, n=98) and White British (WB, n=50). Greatest differences were observed between the PP and WB groups, with BP reportedly

being in the middle. There did appear to be an overlap in the phenomenology of experience between the PP and BP group, suggesting there is a degree of influence of culture. However, their methodology was content analysis of medical records and key worker reports, and thus was based on the perception and interpretation of the HCPs taking the notes, rather than the service user themselves.

Overall, these comparative studies suggest that there are important differences and some similarities between groups in their experience and interpretation of psychosis. However, with the exception of Suhail and Cochrane's work, little research has been conducted to identify differences in the experience of SA residing in their country of origin and the UK. Although Suhail and Cochrane's work is an important addition to the field, its focus on the phenomenology of symptoms and methodological limitations, limits its scope to capture the broader lived experience of psychosis in a UK SA population.

Four studies explored the experience of psychosis in SA migrants. Shame, stigma, discrimination, social and structural barriers were reported to impede help-seeking across these studies. Additionally, illness experiences were reported to influence participation and interaction with the wider SA community (Virdee et al., 2017). Both Virdee et al. (2017) and Weatherhead and Daiches (2010) reported participants attributed MH illness to psychosocial factors (e.g. stress or drug use) and in the context of spiritual/religious frameworks e.g. punishment from God, witchcraft, spirits and black magic. Interestingly, some participants reported that they felt although clinicians were open to hearing alternative perspectives, they did not actively provide any intervention in line with these ways of understanding (Virdee et al., 2017). In Connor et al's (2016) UK-based study in service users experiencing FEP and their family members, participants reported several other barriers to help-seeking, including a negative family response to illness, poor MH knowledge, 'rationalising and normalising' signs of illness and preferences for coping inside the family and using formal and informal support. Pluralistic intervention was also reported by Dein and Sembhi (2001) and Weatherhead and Daiches (2010). Dein and Sembhi (2001) suggest that those migrating to the UK from South Asia maintain traditional values and beliefs, however these are influenced by the process of acculturation, specifically a Eurocentric understanding of illness where there is a high degree of biomedical hegemony.

Weatherhead and Daiches (2010) conclude that current services are ill-equipped to address the co-existence of Western secular and Islamic religious beliefs.

Overall, studies conducted in migrant SA individuals suggest there are several intersecting cultural factors that need to be given further consideration in this population. Current research in this group is limited by heterogenous samples, including mixed ethnic groups (Connor et al., 2016) and heterogenous MH illness experiences and countries of origin (Weatherhead & Daiches, 2010; Dein & Sembhi, 2001) or a focus on a single cultural dimension (Dein & Sembhi, 2001). Notably, no studies identified for this review explored the broad lived experience of FEP in British SA service users, using Interpretative Phenomenological Analysis. This would allow for exploration of an experience from the position of the person, and moves beyond making comparisons based on category membership.

Illness beliefs

When faced with a health-related threat, Carter et al. (2018) propose that one will automatically develop a cognitive appraisal of the problem. Causal explanations are a set of assumptions that one can hold regarding the origin of a particular phenomenon. Explanatory models (Kleinman, 1980) concern the understanding of how culturally shared beliefs influence the understanding and explanation of the illness and its symptoms. Research suggests beliefs about physical and MH impact pathways to care (Patel et al., 1995), and can significantly predict outcomes (Petrie et al., 2008; Lobban et al., 2004). Patel et al. (1995) notes that the response of the individual is usually dependant on the cultural framework that allows them to understand their experiences and which make sense to them.

There is evidence suggesting that service users and carers from BAME groups generally receive poorer services (such as poorer 'responsiveness' of services to service users individual needs such as cultural, linguistic, lifestyles or faith, increased risk of involuntary psychiatric section), poorer quality of services (e.g. inequalities in access, variation in treatment options offered) and poorer outcomes than White British individuals within mental healthcare (DoH, 2005). It therefore seems vital for HCPs to engage with and better

understand service users and their families in a way that matches meaningfully to their understanding of their experiences (Bhui & Bughra, 2002).

Carter et al's (2017) systematic review identified three categories of causal illness beliefs: psychosocial (recent stress, trauma, lifestyle and behaviour), biogenetic (genetics, neurological, disease) and spiritual (God's will, specific cultural beliefs and fate). The authors noted the former two categories appeared predominant in "developed" countries and the latter was most strongly held in "developing" countries. The review also indicated that beliefs can significantly influence the type of help-seeking (e.g. medical, spiritual), treatment outcomes (attitude towards treatment, satisfaction with therapeutic relationship, remission) and contribute to the experience of stigma. However, this review did not include any studies exploring illness beliefs in a FEP sample.

Studies exploring illness beliefs in SA residing in South Asia report spiritual and religious illness beliefs are commonly held alongside psychosocial and/or biological explanations (Dutta et al., 2019; Johnson et al., 2012), and sometimes this can lead to seeking support from traditional and faith healers (Dutta et al., 2019; Ahmad et al., 2017) or using religious remedies such as visiting a healing temple, Dargan (shrine of Muslim saint), priest, maulvi (faith healer with expertise in Muslim law) or astrologer (Chakraboty et al., 2013) before seeking specialist support. Bhikha et al's (2012) review indicates that individuals can hold separate and sometimes paradoxical illness beliefs simultaneously, allowing for sense-making that incorporates culturally sanctioned values and norms and involves seeking pluralistic intervention. This current study can extend these findings and explore illness beliefs in those that have migrated and live in another culture.

Whilst attitudes, values and the belief systems can be transmitted by family/community and intergenerationally, and may contribute to the conceptualisation of FEP, the perceived cause(s) of it, the severity and prognosis, along with treatment preference; country of residence also appears to be a significant factor in the experience of psychosis. In Suhail and Cochrane's (2002) study described earlier, they found local cultural resources (country of residence) explained more difference in content than did ethnic cultural resources (country of origin). This is an important area to examine in the SA community, as not only are they ethnic minorities but they also exist in a different normative environment, the impact of

which has been given little academic attention. There is a risk of British SA experiencing discrimination based on their ethnicity (Major & O'Brien, 2005), but also based on their requirement of acculturation, meaning they are expected to adopt a new culture and its social norms (e.g. MH beliefs) which can be challenging (Sam & Berry, 2010).

Where research has explored illness beliefs in UK populations, several notable differences between UK White British and SA communities have been identified. The seminal work by McCabe and Priebe (2004) explored explanatory models in UK African, Bangladeshi, West-African and White 2nd generation individuals diagnosed with schizophrenia. They found that 26.9% of the Bangladeshi sample and 28.6% of the West-African sample cited supernatural causes vs 0% of the White sample, who largely cited biological causes.

Later, Bhikha et al. (2015) explored illness beliefs in a British SA sample (n=45) using the short explanatory model interview (SEMI). The majority of participants cited a supernatural cause of illness as their first response (n=25), two participants attributed a biomedical cause, one participant didn't know and suspected 'nazar'[4] and 17 participants attributed psychosocial stress, including trauma. A large portion of this sample were seeing a traditional healer alongside medication (n=35) suggesting they held a dual explanatory model of illness beliefs. Interestingly, some participants reported psychosis as a disorder that needed professional help but did not report the symptoms as an illness. This suggests that although individuals recognised the term psychosis, their interpretation of the symptoms or the diagnostic label of psychosis was different from that of a MH professional. These results also suggest that people can hold different and contradictory explanations and treatment models to help sense-making. As this study used the SEMI it might not have fully captured how participants made sense of their experience of psychosis. It can be argued that given beliefs and practices within and between groups are highly variable, can be internally inconsistent, situation driven and dependant on other variables such as SES, ethnicity or religion, the impact of culture in illness belief is hard to assess in a structured questionnaire. The present study will aim to extend these findings by conducting a more in-

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[4] 'nazar' was translated to 'evil eye' in the paper.

depth analysis focussing on how psychosis unfolded and was made sense of in this population.

Broader work exploring family and community illness beliefs of FEP has also indicated culture specific understandings of psychosis and its treatment (Penny et al., 2009; Monteiro et al., 2006) and associated this with delays in accessing formal intervention (Carter et al., 2017; Islam et al., 2015). Along with clinician reports of poor experience and training in treating different cultures (Islam et al., 2015), qualitative studies have identified that there is incongruence between Western and non-Western understandings of distress, that formal services are only accessed at point of crisis and family honour can play a role (Chew-Graham et al., 2002). Sheik and Gatrad (2000) propose that Eurocentric models of care are ill equipped to understand Muslim narratives, such as an Islamic perspective that psychological difficulties such as depression and anxiety are indicative of an unsound spiritual heart. These differences could be mirrored in help seeking behaviours, e.g. HCP vs prayer, religious leader or family support, and compounded by poor cultural sensitivity in MH services.

Incongruence in illness belief models may also have a significant impact on perceived insight in psychosis. Psychoses are often characterised by 'poor insight', where the individual holds a different interpretation of what is happening to that held 'true' by the culture in which they sit (e.g. the medical model in Eurocentric culture). If the dominant clinical language is not taking an individual's experiences into account, it might make it more difficult to understand the phenomena they are encountering and engage with service users' belief systems. Furthermore, alternative conceptualisations may be mislabelled as poor insight and serve to devalue the service user's perspective.

In this context, insight relates to acceptance of a dominant service model, a culturally constructed explanation of experiences that individuals must subscribe to. This may lead to cognitive dissonance and serve to endanger the therapeutic relationship and engagement with services. Indeed, insight in itself is a cognitive and social construction of the self and as such it is profoundly shaped by cultural beliefs and practices. Rather than being a binary concept, insight should be considered in relation to the individual who is experiencing psychosis, their family, health care provider, and the wider social context. In this respect

without stereotyping, insight has to be understood as context dependant and as a response to the cultural meaning of the psychotic experience.

Overall, research suggest there is variation in the epidemiology, DUP, service access and engagement and recovery for those belonging to a SA ethnic minority group. However, methodological limitations and underrepresentation of this group in samples restricts drawing firm conclusions. Significantly, research demonstrates that the experience of psychosis can vary across groups. Exploration of illness beliefs suggests that religious beliefs can affect how individuals conceptualise their experiences (and this may be at odds with a Eurocentric system) and understand the causes of illness. Cultural beliefs and norms can affect how the individual and those around them perceive MH difficulties and help-seeking resources. Furthermore, it appears that explanatory models are not mutually exclusive, multiple explanations can be held simultaneously, and treatment within this population can be pluralistic. However, relatively little is known about the broad experience of FEP in British SA and if and how different explanatory models interact with each other to influence help-seeking, illness experiences and recovery. It appears that whilst our knowledge of alternative illness explanations is increasing, this has not been translated into improvements in access to care and outcomes for SA service user's (Fitzpatrick et al., 2014). To address this issue, an exploratory study was conducted focussing on how British SA individuals make sense of their experiences of FEP, within the context of a particular cultural and service delivery setting.

Chapter 2

- Methodology -

This chapter will begin by providing a brief introduction to exploring the lived experience, it will then outline qualitative approaches and provide justification for the chosen approach, Interpretative Phenomenological Analysis. It will also provide a detailed summary of the research context, design and process along with an explanation of the ethical considerations.

Exploring the lived experience

There are two somewhat divergent ideologies in which cross-cultural research can be approached, although they are by no means mutually exclusive, and both hold value. Etic and emic are neologisms introduced to anthropology from linguistics (Mostolamsky & Rota, 2020) and relate to how cultures can be studied. It can be said that the conceptualisation of psychosis has largely been based on 'etic' knowledge, in that it has been typically, and some would argue continues to be defined by those that have not themselves had lived experience of the phenomena. In this sense, the research is approached from an observer or theorist perspective (Davidson et al., 2004). Under the etic perspective, it is argued that mental illness is a universal concept under which Western instruments and diagnostic criteria are perceived to be globally valid and applicable. The 'emic' approach looks to obtain knowledge via those with lived experience, and places value in the subjective viewpoint. An emic perspective can be utilised to examine the local cultural context in which psychosis occurs.

Given that the experience of psychosis in those from a SA background is relatively under explored, and in order to ethically utilise the lived experience to inform our understanding and healthcare provision, a qualitative inquiry from a phenomenological perspective is likely to be best suited.

Justification of methodological approach

Qualitative approaches are often used for the study of lived experiences and situational meaning and are recommended for research that requires initial exploration. A qualitative approach will allow for the investigation of how people make sense of their experiences via the collection of open, reflective and informative responses. In this study, it will allow for an in-depth exploration of the rich complexities and nuances of the experience of psychosis in a SA population from the perspective of those being studied (Elliot et al., 1999). As noted by Chamberlain et al. (2008) the aim in qualitative research is not to predict, but rather to describe and understand experiences. This method of research is rarely, if ever, value-free (Carr, 1995), and the researcher's own values and assumptions will inevitably influence perceptions, the positions taken and the methodology and methods adopted. Therefore, it is explicitly acknowledged that the methodology is driven both by the research questions and the researcher's own theoretical assumptions (Lyons & Coyle, 2016).

Theoretical underpinnings of qualitative methodology

Epistemological philosophies that underpin qualitative methodology, lie on a continuum, with several positions between the poles. Each position provides a different means of explaining how knowledge is acquired, and how one makes sense of the world. A realist/positivist position argues that objective reality is discovered via objective processing such as observation and deductive reasoning. On the other hand, a radical constructionist position, argues that there are multiple identities, and these are produced and maintained via social and cultural processes. Between these positions, there is contextual constructionism, which proposes that knowledge is a context-dependant construct. In that a single phenomenon can be understood in multiple ways, depending on the idiographic perspective of the individual, and therefore all knowledge is provisional and relative (Madill et al., 2000).

Of the three philosophies, the two that sit at either end of the continuum of knowledge acquisition do not fit within the aims of this research study. The realist position does not consider an individual's lived experience of a phenomena, in this case psychosis, and the radical position focusses on the way language and discourse shape experience and the self

and argues that there is no absolute basis for knowledge. The contextual constructionist position fits best with the aims of this research, given its focus on the experience of psychosis from a subjective viewpoint. Adoption of this position allows for the exploration of an individual's experience in the knowledge that the researcher is not attempting to reveal one objective reality. Within this position, it is the responsibility of the researcher to characterise the perspective of the participants, ensuring that findings are grounded in their actual representations (Tindall, 1994).

In the adoption of an epistemological position in qualitative research studies, it is also prudent to consider one's ontological position. Ontology is concerned with the nature of being and reality (Smith, 2004). This too exists on a continuum, broadly categorised under realist, relativist and anti-realist positions. A realist position argues that there is a single, objective and independent reality, which individuals have a linear relationship with and that what is perceived is the "true" world (Willig & Rogers, 2017). An anti-realist position argues that reality is only ever subjectively constructed and there are no objective values or normative facts. A relative-realist position is adopted, as this study is not concerned with producing a true objective account and aims to gain an understanding of how individuals make sense of their experiences of psychosis from a subjective standpoint.

Methodological frameworks

There are several methods, tools and approaches for collecting and analysing data in qualitative research, each of which come with their own philosophies and advantages/disadvantages. Grounded theory, discourse analysis, narrative analysis, and interpretative phenomenological analysis are considered amongst the main approaches and there is a degree of overlap between them (Lyons & Coyle, 2016). Grounded theory (Glaser & Straus, 1967) aims to develop a theoretical account of a particular phenomenon (Smith et al., 2009). This approach would have been appropriate for this study, if the aim was to develop a theory about the process by which ethnicity affected the experience, development and maintenance of psychosis. Discourse analysis is primarily interested in power, interaction and communication and is based in the social constructionist school of thought (Smith et al., 2009). Although this method can be considered appropriate for this study, the primary aim here is to interpret the sense-making of individuals within their

contexts, and not to focus on language used and discursive representations. Narrative analysis is also a method rooted in social constructionism and is primarily interested in the content of people's stories, the structure of narratives, and the constraints and opportunities placed within them (Smith et al., 2009). This is an element of this research. However, although participants are invited to share their narrative, the primary aim here is to explore how individuals have made sense of their experiences.

Interpretative Phenomenological Analysis (IPA)

A central aim of IPA is to obtain a detailed narrative of a given phenomenon from the person who has lived experience of it. IPA allows for the systematic interpretation of these narrative accounts to help us understand the meaning individuals have ascribed to their experiences (Smith et al., 2009). The central aims of IPA are therefore twofold: to obtain an 'insider's perspective' of the phenomena under study via listening intently to the experiences described by the individual experiencing it and to attempt to interpret the accounts to gain an understanding of what sense people have made of their experiences within their context (Larkin et al., 2006). IPA is a widely utilised methodological approach, exploring empowerment in young people with psychosis (Grealish et al., 2013), mindfulness groups (Dennick et al., 2013) voice hearing (Rácz et al., 2017), delusions (Todd et al., 2010), stigma and psychosis (Knight et al., 2003) and trauma and psychosis (Dunkley et al., 2015). However, it is yet to be used to explore the broad experience of psychosis from the perspective of SA individuals.

Theoretical underpinnings of IPA

The three central theoretical concepts of IPA are phenomenology, hermeneutics, and idiography (Smith et al., 2009). Phenomenology is concerned with the examination and understanding of people's lived experience. The aim is to be transparent about fore-conceptions and actively incorporate this into the research and analysis process via reflexivity. One way is via "bracketing" (Husserl, 1927), referring to separating the researcher's preconceptions to gain a deeper understanding of an individual's reality. However, this has been challenged (Smith et al., 2009) and therefore the concept of "bridling" (Vagle, 2009) will be adopted, referring to reflecting on the process of conducting

the research and how sense was made of the data. The second theoretical underpinning concerns hermeneutics. A double-hermeneutic position is adopted, in that there are two levels of sense-making: "whereby the researcher is trying to make sense of the participant, trying to make sense of what is happening to them" (Smith, 2011). The third theoretical underpinning of IPA is idiography. Under this concept, less concern and attention is given to making claims that are generalisable at a group or population level, but rather to the process of intensive and detailed analysis of each case individually (Larkin et al., 2006) to create a personal account of a phenomena. In this study idiographic commitment will be demonstrated via the inclusion of extracts from the transcripts to illustrate individual experiences and sense-making. Whilst single-case studies can provide valuable perspectives, Smith et al. (2009) describes a process of also achieving the idiographic element via a detailed examination of individual cases which are then subjected to cross-case analysis to explore convergence and divergence (Smith et al., 2009). The aim of this study is to demonstrate existence rather than incidence (Smith et al., 2009) and show us that, or how something *is.* Its aim is to help identify any flaws in existing theoretical claims for a population, and ways to revise theory and practice.

Rationale for selection of IPA

IPA allows for a potentially deeper insight into what people have experienced, how they have constructed their world, and factors they think and believe are important in their understanding of why they have experienced psychosis in a certain way. In this way, participants are themselves encouraged to (re)interpret their lived experience and reflect on the conditions that surround their psychotic experience in reference to past events and histories, but also in the context of their social-cultural framework to help us understand the cultural position of the experiences. An IPA approach also sits well with the epistemological position of contextual constructionism, as noted earlier, as the focus here is not on obtaining objective knowledge but recognising that knowledge is context dependant in which the researcher/interpreter plays an active role.

A key consideration in the adoption of IPA

One noteworthy 'limitation' of IPA in this research context is its reliance on language, specifically the availability of language to articulate one's experiences and then the interpretation of that. IPA critics argue that language is limited to telling us how people talk about their experiences rather than their understanding of the actual experience (Willig & Rogers, 2017). IPA proponents acknowledge that meaning-making takes place in the context of narratives, discourse and metaphors and that whilst the primary aim is to gain insight, this is intertwined with language (Tuffour, 2017). Smith et al. (2009) propose that how one talks about experiences can be directly linked to how one feels and thinks about them, and therefore there is a role for the researcher to interpret this in order to gain an understanding of how the individual has made sense of their experiences (Smith, 2011). One could also argue that this central critique is further complicated by the addition of the researcher's active role in the analysis and interpretation process, which Brocki and Wearden (2006) argue is limited to the researcher's ability to interpret, reflect and make sense of the data. However, as with other methodological approaches, comprehensive analysis guides are available to aid the researcher in the clear, transparent and systematic process of data analysis (Smith et al., 2009). What is appealing about this process is that IPA allows for flexibility and does not advocate for the strict prescription to the steps and stages in a linear fashion, instead to treat the data in an iterative and interactive manner guided by the general principles underpinning this methodology.

The lived experience of psychosis: the research aim

Following, the recommendations of Pietkiewicz and Smith (2014) regarding epistemological reflexivity, defining the research question was followed by development of the research design and interview schedule. During this process the following research aims were taken into account:

- to elicit the lived experience of psychosis. Its aim is not to develop a theory or construct of psychosis, nor causal relationships, associations, or explanations.
- to investigate people's broad experience of psychosis, in the context of the service setting and their cultural and ethnic background, rather than a study of psychosis in isolation.
- to elicit a deeper understanding of the lived experience of psychosis in those from a marginalised population.
- to be embedded in the phenomenological paradigm and use emic knowledge.
- to be transparent regarding pre-existing fore-conceptions of psychosis and SA ethnicity, given the researcher's own knowledge and experience of people living with psychosis and ethnic background.

This process led to a broad primary research question:

How do British South Asian individuals experience and make sense of psychosis?

Method and Procedure

Research Design

This study is utilising IPA to re-examine assumed knowledge. As outlined in the previous section, IPA uses a qualitative approach for the detailed examination of the lived experience of a phenomenon; in this study this is the exploration of the lived experience of psychosis in individuals who self-ascribe to a SA ethnic minority group.

Research Context

This research was carried out in an Early Intervention Service for Psychosis in West Yorkshire, United Kingdom. West Yorkshire is home to several immigrant communities from South Asia (ONS, 2011). It is therefore considered an appropriate location to undertake research relating to this population. It is noteworthy that the district within which the study was conducted experiences significant discrepancies in social poverty and inequality compared to the rest of the nation (Health and Wellbeing Profile, 2020). There is a large SA population within this area and quantitative data evidencing major gaps and unsustainable pressure on psychiatric support, and poorer engagement of MH services within the SA community (Mental Wellbeing Profile, 2016-2021; Tackling Health Inequalities for BAME Communities and Colleagues, 2020). As is the case more broadly in the NHS, this district also notes poor workforce diversity. Only 21% of the NHS workforce identified as from a BAME background, with even fewer in senior positions (19%) (Equality, Diversity and Inclusion Annual Report, 2020).

The EIS works with individuals between the ages of 14 and 65 years old who are experiencing FEP. Table 1 illustrates ethnicity of patients discharged between 2016 – 2018, reflecting the demographics of the district. EIS provide a three-year early intervention programme during which time service users can access psychological therapies, medical and social interventions. The aim is to provide an MDT service to facilitate support and recovery and improve everyday functioning. Staff include a range of HCPs such as social workers, clinical psychologists, occupational therapists, support and development workers and psychiatrists. Although recruitment from charities and other NGOs was considered to include as many different and diverse voices as possible, it was ultimately felt to be

unsuitable due to the requirement of obtaining a degree of relative homogeneity in the sample.

Ethnicity	Current Caseload	Duration of involvement with EIS (mean days)
Asian Pakistani	**97**	**986**
Asian Bangladeshi	**77**	**971**
Asian Indian	**6**	**898**
Asian Other	15	751
African	10	652
Black Caribbean	5	873
Nigerian	2	338
Black other	4	893
White British	**154**	**856**
White other	25	687
Arab	2	889
Former USSR	3	1295
Other	13	915
Not Known	43	787

Table 1. Demographic information for Early Intervention Service.

Sampling

Within the IPA approach, it is stipulated that the sample consists of a homogenous set of participants who have lived experience of the phenomena being explored, whilst avoiding 'identikit' participants (Smith et al., 2009). This is to allow for a level of convergence and divergence in individual accounts and the development of shared sense-making of experiences. Due to its idiographic nature and in-depth analysis of individual cases and experiences, relatively small sample sizes are deemed appropriate for IPA research designs. Smith et al. (2009) recommend between six to ten participants is an acceptable range for IPA. With this in mind, this study used a purposive sampling to identify a relatively homogenous group. For this research study this included individuals experiencing psychosis and self-ascribing to a SA ethnic minority group. No exclusionary criteria were applied regarding participants emigration status (e.g. those seeking asylum, 1st generation, 2nd generation etc.). Inclusion was regardless of gender, sexual orientation or disability and other protected characteristics.

This aim of this study is to provide a degree of 'theoretical transferability' whereby, links can be made between individual experiences, the collective findings and the existing literature, thus allowing for a more comprehensive understanding of a phenomena (Smith et al., 2009). The aim here is not to create a generalisable, definitive account of the lived experience of psychosis in SA people, but to explore and contribute to the emerging picture regarding the impact of ethnic and cultural nuances on lived experience. It is anticipated that these results can be synthesised to begin to form a more comprehensive picture of the experience of psychosis in different BAME groups, which may help develop culturally informed practice. Some demographic information will therefore be provided to allow for transparency and to build a picture of the experience of psychosis in people from a marginalised group.

Data Gathering

There are several methods of gathering data, of which focus groups, structured interviews and semi-structured interviews are popular. Whilst focus groups would allow for the collection of data from multiple participants simultaneously, this may be limited by group dynamics and interactions. In the context of personal experiences, a group setting may hinder sharing, for example if they are distressing. Structured interviews on the other hand, would allow for focussed data collection via predetermined categories. However, these may be overly constrained and limit the phenomenological exploration of complexity and ambiguity (Smith, 1996). Semi-Structured interviews would allow participants to guide the interview, raise topics pertinent to themselves and create their own narrative about their experiences, whilst maintaining a scaffolding around areas relevant to the research aims (Smith et al., 2009). However, they are limited, in that the researcher has less control, interviews can be lengthy, and analysis is more complex (Smith & Osborn, 2007).

As little is known about the lived experience and meaning-making of psychosis in those from a SA minority group, it seems appropriate to allow participants flexibility in their answers. A semi-structured interview method seems to be the best approach to eliciting information about psychosis to allow the participant to create a rich and nuanced picture (Smith, 1996).

Semi-structured interview schedule

A semi-structured topic guide (appendix I) was developed in an iterative manner based on the researcher's clinical and research experience, the current literature, support from supervisors, colleagues and service user consultants (see below). The aim was for the questions to be open and general in order to avoid leading questions or imply there is a right or wrong answer. The opening questions were designed to invite the participant to talk about why they wanted to take part in this research and the first time they noticed or felt something was different. Further questions, prompts and probes were developed to be used flexibly depending on what the participant discusses in order to explore their experience of psychosis in more depth.

Service user consultation

Consultation on the study documentation (e.g. Participant Information Sheet (PIS) and Consent Form) and semi-structured topic guide was provided by one service user group (a Hearing Voices group) and the Leeds Help from Experts by Experience for Researchers (HEER) group. Both groups were approached prior to ethical approval and data collection. Both groups included a mixed ethnicity demographic. Each group started with a short presentation by the researcher outlining the study, followed by a discussion of acceptability of the study concept. This was then followed by dissemination of the study documentation and participants were given time to look through and note any comments, in writing and verbally. The hearing voices group commented that the topic guide appeared sensitive and understandable, and that the questions were appropriate in the context of the aims of the research. Service users remarked that the PIS was a lengthy document but was understandable and acceptable. One service user mentioned that some participants might need further clarification and reassurance regarding the use of audio recording equipment, which was noted. One service user suggested amending the phrasing of item 6 in the consent form to replace the word harm with risk.

The HEER group made some detailed comments on the PIS:

1. Sense-making changed to understanding in title.
2. Wording changed to say they have experienced psychosis.

3. Wording changed to clarify withdrawing. Defining what is meant by transcription, anonymised and analysed.

4. Adding where the interviews will be held.

Additional changes were made to the consent form wording to make it more understandable.

No significant concerns were raised about the topic guide.

The HEER group strongly recommended offering two interviews to each participant to allow for reflection and to ensure that a complete narrative was captured regarding the participant's experiences.

The interview schedule was also discussed with supervisors and an IPA consultant. It was also practiced with fellow trainee psychologists on the course, to test for phrasing, order and content. Suggestions have included adding an introductory question, changing phrasing of question 1 to allow for a broader introduction to the topic and allow for the participant to lead the discussion, and rephrasing two questions that were felt to be closed questions. Some feedback was received to ask questions about impact of culture and ethnicity more directly and earlier on in the schedule.

Procedure

Recruitment

Key to recruitment was the support of MDT staff within the service who were working directly with the service users and acted as gatekeepers for the purposes of this research study. Research awareness presentations were provided to staff from the three EIS clusters and to socialise the potential gatekeepers into the research process. During these meetings staff were provided with a Staff Information Sheet (appendix II) and a chance to ask questions.

The Gatekeepers' role was to serve the interests of the service users and was independent of the research. They were provided with detailed information about the study and regarding the inclusion and exclusion criteria. They had the power to deny research access

to the participants if they believed the participants would not have the capacity to consent or be at risk if they were to do so. This was to ensure protection of vulnerable people from the pressure of the research process.

Staff were informed of the following inclusion and exclusion criteria:

<u>Inclusion criteria</u>

- Capacity to provide informed consent (as assessed by gatekeeper involved in their care).
- Experience of psychosis.
- Are able to engage in an interview about their experience with psychosis.
- South Asian ethnicity, from three broad self-ascribed ethnic groups: Bangladeshi, Indian and Pakistani.
- Ability to converse in English (as determined by gatekeeper).

<u>Exclusion criteria</u>

- Unable to provide informed consent
- Would be at risk of becoming significantly distressed if they took part in the study (based on the clinical judgement of gatekeeper involved in their care).
- Currently experiencing features of florid psychosis, that would make it difficult to engage in an interview.
- Under 18 years old.
- *Not able to converse in English.

*IPA relies on a very detailed interpretation of the language participants use to convey their experiences. In this context, the understanding of the richness and nuances conveyed is dependent on both the participant and researcher sharing a language, in this case English. Exploring this in a SA population, where another, perhaps first language, is present was given careful consideration. Although an interpreter could have been used, this would add a second level of interpretation and may have impacted the rapport between the participant and the researcher. As such, for the purposes of this study, the service user had to speak

English to a sufficient level to take part in the interview. This was determined by the gatekeeper who initially identified the service user and assessed capacity to consent.

Participants were welcome and encouraged to use their own language to describe or label their experiences, in each case the interviewer asked for further clarification and the participant was able to provide a translation in English to capture the meaning. It is acknowledged however that in this translation linguistic nuance can be lost. Where a second language was used, terms were also discussed with the cultural consultant to provide a clarification that was as accurate as possible.

The gatekeepers were provided with Participant Information Sheets (appendix III). If they identified a service user who met all of the inclusion criteria and none of the exclusion criteria, they would approach the service user about the study and provide the PIS. At this point, the gatekeeper was asked to encourage the service user to think about whether or not they wish to take part and discuss with their care team, family and friends etc. Service users were given a minimum of 48 hours after receiving the PIS before they were approached by the gatekeeper to discuss potential participation. If they deemed the service user had capacity to consent to talk to the researcher, they would request permission to provide contact details so that the researcher can approach the service user.

As the researcher, there was no direct contact with any service user until they had been approached by the gatekeeper, assessed for capacity to consent to the sharing of contact details and study participation, and on being informed about the study through the PIS. After this point gatekeepers shared a contact number via NHS email. To maintain confidentiality no names were exchanged at this point.

The participant was then contacted to discuss the study and consent in more depth (at which point they shared their name). In keeping with the recommendations regarding COVID-19 and guidance released by NHSx Information Governance all study participants were offered the option to participate in the study via approved virtual methods such as Telephone, WhatsApp, FaceTime, Skype and commercial products designed specifically for this purpose e.g. Zoom. Information Governance NHSx had advised that under these circumstances consent to use these methods was implied by the individual accepting the

invite. The researcher abided by any guidelines stipulated by the Trust, the EIS and the University of Leeds regarding participant contact and approved methods of communication.

An interview appointment was arranged to take place virtually via Zoom or telephone, or at a venue acceptable to the participant and risk-assessed for research purposes. The gatekeeper who referred the service-user was informed of this in order to provide a post interview 'check-in' and offer support if required.

Participants

This study used purposive sampling to recruit service users who self-ascribed to a SA ethnic minority group and have a primary presenting problem of psychosis. Fifteen service users initially expressed an interest in taking part in the study. Of which five service users declined after the initial telephone meeting with the researcher: two of whom did not want to take part in a study of this nature, one was too busy as they were starting a new course and two were concerned about confidentiality.

Ten interviews were conducted of which two interviews were omitted from the analysis; one participant was extremely drowsy and was not able to concentrate sufficiently enough to answer the initial opening questions and therefore it felt unfair to continue with the interview. This participant declined an offer to reschedule. Another participant demonstrated a poverty of speech and a real struggle to recall their experiences and make sense of them. Although this interview lasted approximately 28 minutes, responses were mostly silence or "*I don't know*", which would make identifying and grounding any themes difficult. IPA relies on language, and although this participant had an interesting and valuable story, at the time of the interview they were not able to communicate in way that could then be interpreted at a sufficient level for research. This participant declined an offer of a follow-up interview as they felt they had said everything they wanted to say. For both participants ethically their views could not be represented, even though they were interviewed as part of the study. Both participants demonstrated capacity to consent but could not provide content of a sufficient quantity. As with other study participants both gatekeepers and the researcher assessed capacity to consent over the research process.

Their gatekeeper was informed of the interview process and the researchers' reflections on it and it was agreed for the gatekeeper to contact the participants to 'check-in'.

Overall, this study had a sample of eight participants. **Identifying details have been removed and all the participants were allocated an anonymising number (known only to the researcher) and a pseudonym to be used for verbatim excerpts.** Any other names the participant used (e.g. in reference to their care-coordinator) have been omitted.

As noted earlier, IPA samples strive for some degree of homogeneity within small samples. For this study there were two points of homogeneity, in that all participants accessed EIS for psychosis and self-ascribed as South Asian (seven of the eight participants were from a British Pakistani ethic group, with one from a British Bangladeshi group). Although not a diverse sample regarding the SA community, it is representative of the area and the service in which the study was undertaken. There were three men, four women, and one non-binary participant, with ages ranging from 19 years to 40 years with a mean age of 25.9. Asim and Nazreen at 19 years and Salma at 40 were at the extremes of the age range.

Participants had been with EIS for between 1 to 3 years at the time of their interview(s) and the majority had a primary diagnosis of First Episode Psychosis. Ismail, Asim, Sophia and Amina had accessed Child and Adolescent Mental Health services prior to their referral to EIS. Salma, Amina, Dalil and Asim were currently experiencing perceptual anomalies (voice hearing and/or visual anomalies). Ismail had heard voices in the past but described no longer hearing them, his primary current difficulties were around paranoid ideas and thoughts. Both Sirah, Nazreen and Sophia described no longer experiencing any perceptual anomalies; Sophia's recovery is ongoing, and she continues to take medication to help with her mood. Nazreen continues to manage bi-polar disorder, with the help of medication.

All participants reported being born in the UK with fathers born in Pakistan, with the exception of Dalil, whose father was born in Bangladesh. Ismail, Sirah and Asim's mothers were born in the UK; Nazreen, Salma, Sophia and Amina's mothers were born in Pakistan, and Dalil's in Bangladesh. All participants reported parents had immigrated to the UK 15+ years ago.

Five interviews were conducted in person and three interviews were conducted virtually. Five participants attended a second interview, three of which were conducted virtually and two in person. Two participants declined the offer of a second interview, and one participant consented to be contacted for a second interview but was not reachable. Demographic details collected from each participant, and with permission verified by their gatekeeper can be found in Table 2.

Interview process

Informed consent was obtained in written from (appendix IV), where interviews were conducted in person, and verbally where interviews were conducted virtually. For verbal consent, participants were asked to explicitly consent to each statement of the consent form, read by the researcher and recorded on an encrypted recording device.

Where virtual interviews were conducted, during the process of setting up the interview, the researcher asked the participant to confirm they were in a private room to maintain confidentiality and if they were happy to provide their location (e.g. at home) in the event that they require immediate emergency support. For any interviews conducted virtually participants had the option to turn the camera off.

Data Collection

In order to build rapport and familiarise the participant with the interview process, the interview began with an introductory question, and was followed by open questions to elicit the phenomenology of the experience. The aim of the interview was to maintain a broad focus on the overall experience of psychosis and the participants' reflections on the relationship between their experiences and ethnicity, culture and religion. The interview schedule was designed to be open and flexible, with prompts for encouraging dialogue, and was not designed around an existing theoretical framework.

Once the interview was completed the encrypted device was switched off and the participant was debriefed. At this point the researcher asked the participant how they were feeling, if there was anything they found difficult or distressing and reminded them of the details in the PIS, should they wish to access support. After the interviews, with the

participant's agreement, the researcher asked them to provide some brief additional information. Where participants were unsure, consent was sought to ask their gatekeeper. The following information was requested:

- Age
- *Ethnicity
- Year of first contact with mental health services
- Length of time with the early intervention services
- Current/ most recent diagnosis
- Country(s) of birth of service user and parents

All participants agreed to provide the demographic information, and for it to be checked with their gatekeeper where they felt unsure. *All participants were asked how they would describe their ethnicity; this was left open to them and no categories were provided in advance. Participant's religious beliefs were not included as part of the study criteria or in the collection of demographic information. The aim of this study was to explore broad identities within a South Asian group, rather than specific religious identities. Participants were asked to reflect on the impact of their ethnicity, culture and religion and often did so in respect to faith and practice, rather than a specific religion itself.

At the end of interview one, study participants were offered a second interview to take place approximately one week later. The gatekeeper who assessed capacity to consent to interview one was informed in order to assess if capacity was retained between the two interviews. It was agreed that if the gatekeeper determined the participant had lost the capacity to consent between interviews one and two, they would inform the researcher of this, and the participant would be withdrawn from further participation. Data collected with informed consent from interview one would be retained and used in the study. However, no further data would be collected.

Individual interviews (one and two) lasted between 12 minutes and 120 minutes. After each interview, the researcher, made initial reflections of the interview and the participant. All interviews were digitally audio recorded using an encrypted device and transcribed verbatim. The researcher transcribed the first interview, for initial analysis and

familiarisation with the data. Subsequent interviews were transcribed by University of Leeds approved transcribers, who signed an agreement stating they will maintain confidentiality. Each transcriber was provided with a set of instructions (appendix V). Where a participant had attended two interviews the transcriber was instructed to place both interviews into one transcript. Once each transcription was available the researcher listened to the audio recording with the script to check for accuracy. Although IPA focusses on the content of the interview, some prosodic aspects were noted (where appropriate), such as significant pauses or non-verbal utterances as this may aide interpretation.

Table 2. Table of participant demographics

Participant and diagnosis	Age	Ethnicity	Gender	Year of first contact with mental health services (year)	Length of time with the early intervention services (months)	Living situation	Country(s) of birth of participant and their parents	Data collection	
								Interview 1	Interview 2
Ismail; Schizoaffective Disorder	21	British Pakistani	Male	2017	15	Lives with parents	Ismail-UK; Mother-UK; Father-Pakistan	In person	Declined offer
Sirah; First episode Psychosis	23	British Pakistani	Female	2018	28	Lives with parents	Sira- UK; Mother-UK; Father-Pakistan	Virtual	Virtual
Asim; First episode Psychosis	19	British Pakistani	Non-binary (he/him)	2015	12	Lives with parents	Asim-UK; Mother-UK; Father-Pakistan	In person	In person
Nazreen; Bipolar affective disorder, Mania currently in remission	19	British Pakistani	Female	2018	24	Lives with parents	Nazreen-UK; Mother-Pakistan; Father-Pakistan	Virtual	Virtual
Salma; First episode Psychosis	40	British Pakistani	Female	2017	30	Lives alone	Salma-UK; Mother-Pakistan; Father-Pakistan	In person	In person

	Age	Ethnicity	Gender			Living	Birthplace		
Dalil; First episode of psychosis & Emotionally unstable personality disorder borderline type	28	British Bangladeshi	Male	2018	15	Lives with partner	Dalil-UK; Mother-Bangladesh; Father-Bangladesh	Virtual	Accepted offer, not reachable
Sophia; First episode Psychosis	36	British Pakistani	Female	2014	26	Lives with parents	Sophia-UK; Mother-Pakistan; Father-Pakistan	In person	Virtual
Amina; Paranoid schizophrenia complicated by poly substance misuse	21	British Pakistani	Female	2016	36	Lives with parents	Amina-UK; Mother-Pakistan; Father-Pakistan	In person	Declined offer

Ethical Considerations

This research was conducted in line with the Code of Human Research Ethics (BPS, 2010).

The study has been approved by Yorkshire & The Humber - South Yorkshire Research Ethics Committee (REF: 20/YH/0153) (appendix VI). Approval was also obtained from the Research and Development department (appendix VII) and the head of Clinical Psychology (appendix VIII) of the research site.

Informed consent

The use of independent gatekeepers who were separate from the research process was key in accessing a vulnerable population. All gatekeepers were MH professionals, working directly with the potential participant. Gatekeepers provided informal risk and capacity to consent assessments. Decisional capacity was discussed during the NRES Ethics Committee panel, and it was agreed the combined experience of the gatekeepers and researchers clinical experience was sufficient and therefore no formal measure was required. Capacity was checked over the course of the participants' involvement in the research process. If participants appeared to be unable to understand or retain the information, then the researcher would not continue with the interview.

Payment

Participation in this study was completely voluntary. Under no circumstances were any participants pressured or coerced into taking part in the research. Participants were offered a £15 gift voucher following the interviews as a gesture of good will to thank them for their time and effort. This amount was decided based on guidelines from the MHRN Service Users and Carers Payments Policy (2010). To avoid the payment being perceived as a coercive influence, it was not included in the recruitment process, and was offered after the interviews.

Maintaining privacy and confidentiality

An encrypted device was used for audio recordings. Recordings were transferred to the University of Leeds password-protected secure server and deleted from the device. The recordings will remain on the secure server for three years, after the completion of the study. Pseudonyms have been used and any direct quotes are anonymised.

All personal information was kept strictly confidential and stored in accordance with the guidelines stipulated by the University of Leeds, the Health Research Authority, the NHS trust involved and in line with Data Protection Act 2018. Due to the COVID-19 restrictions in place at the time of the data collection, consent forms and voucher receipts were kept in a locked cabinet before being transferred to University of Leeds premises.

It was agreed that confidentiality would be broken if the participant disclosed something that put themselves or others at serious risk of harm (e.g. disclosure of the intent to cause significant harm to self). Participants were advised of when confidentiality would be broken prior to consent and should such sensitive information need to be disclosed to a third party (e.g. GP), the participant would be advised of who this information is being passed on to. This was to ensure the participant was aware of who holds this sensitive information and to maintain an open and honest relationship with them about the use of information about them. It was also stipulated that where a serious risk to self or others was disclosed, the researcher would discuss the matter with and seek supervision from co-investigators Dr Alastair Cardno and Dr Tomas Isherwood, or from Dr Anita Brewin who was the head of Clinical Psychology for the District Care NHS Foundation Trust and is a qualified clinician (Consultant Clinical Psychologist). This was to ensure all necessary actions were taken to ensure the safety of those at risk. Where immediate risk was present, the researcher would use knowledge gained from NHS training in risk management to manage the situation until further support is accessible (e.g. contact emergency services or negotiating the removal of medication in the case of risk of overdose to reduce access to means). Following a disclosure by one participant, with their permission their gatekeeper was asked to check-in with them.

Withdrawal

The right to withdraw at any time was made clear to participants in the PIS, included in the Consent Form, and explained verbally when the researcher met with each participant (e.g. prior to consent and during debrief). Participants were supported in their decision to stop the research they were engaging in (e.g. mid-interview) and/or have their data withdrawn from the study (i.e. not used in the analysis or any publications). Participants were informed that they had up to one week after each interview to withdraw their data. After this time, the interview was transcribed, anonymised and analysed, and it was no longer possible to withdraw their data. Participants were made aware that their right to withdraw would not affect the service they received now or in the future, and their decision would be respected. No participants withdrew their data.

Emotional distress

A protocol was devised jointly by the researcher and EIS staff (appendix IX) to ensure there was a procedure in place during and after the interviews to reduce any potential for harm. In the event of any signs of distress noticed by the researcher during the interview, this was discussed with the participant, they were offered a break or to end the session altogether. The researcher ensured that the decision to stop was the participant's, but in the event of multiple signs of distress or significant distress (regardless of whether this was directly linked to the research) the researcher made the decision to end the session by gently and empathically suggesting that it was the best course of action and suggesting to perhaps rearrange the session. All participants were debriefed after each interview.

As this study was exploring the views of participants who might already perceive themselves as marginalised and/or misunderstood by policies, professionals and services that are intended to help, and the researcher is part of this system, it was important to explicitly recognise the power relationships in utilising qualitative interviewing and participant observation. It is hoped that building rapport and being transparent (about the research purpose) may have helped reduce any sense of the power imbalance between the researcher and participant.

Sensitive topic area

It is possible that some of the topic areas were upsetting for the participants to discuss. Particularly difficult experiences associated with their MH. The researcher was experienced in working with this client group within a research context. A plan was in place to discuss any distress reported or observed with the participant and their care team would be informed if necessary. Upsetting experiences were discussed during the interview, but none needed to be escalated to participants' gatekeepers.

Researcher safety/lone-working

All in-person interviews were conducted on a premises used by the EIS team, known to the participant, and risk assessed for research purposes. They were compliant with the COVID-19 guidelines. The researcher followed the University of Leeds Safe Working Policy to minimise risk to herself. The researcher liaised with the gatekeeper (who identified the study participant) prior to and on the day of the interview to check for any information concerning risk. The researcher planned to utilise any information about current or past risk to make a decision about whether it is safe to meet the participant.

A brief reflection on the researcher's position

Given past clinical and research experience, and my own ethnicity, as a British born Indian I held certain assumptions and expectations going into this study. I believed psychosis would largely be appraised negatively and associated with a chronicity and persistent stigma. I also believed religion and culture would play a significant role in the content of the experiences, beliefs about them and help-seeking. This was fuelled by literature, anecdotal discussions with service users and clinicians, and my personal experiences of belonging to a SA community. This is likely to have influenced some of the interview questions asked and therefore the responses elicited, and which responses I privileged and therefore explored further. It is also likely to have impacted the salience I placed on responses, and thus themes identified.

I also wondered about the potential impact of visible similarities and differences between myself and study participants, such as what position they were put in by sharing their experiences with someone who is also South Asian and identifies as female. For some participants I felt that having some visible similarities helped create a safe space to share experiences and appreciate cultural nuances. However, in this respect I was conscious of prompting the participants to explain what they meant in their words rather than assuming we perceived and experienced things the same way (e.g. cultural norms of arranged marriages, strict parenting or religious practice). Perhaps there was a gendered element to this, in that I did sense some hesitation and embarrassment in some male participants to go into details for example about relationships or trauma experiences. I hope that open discussions with supervisors and the cultural consultant highlighted where bias was present during this process.

Chapter 3

- Data Analysis and Interpretation -

The following chapter presents the stages of analytic process involved in the identification of the superordinate and subordinate themes that led to the formation of the findings. While the analysis for the most part focused on the participants' experience, in keeping with the two-fold nature of IPA, the researcher's interpretation is presented alongside this.

Guidelines outlined by Smith et al. (2009) informed the analysis process. Data from each interview was initially worked with in isolation to extract the sense-making for the participant and the researcher, with the emphasis placed on the participant. Post-interview reflections were revisited at the start of the analysis process for each participant. Each transcript was read several times whilst listening to audio recordings, to initially check for transcription accuracy, to re-immerse in the data and take notes of things that were noticed in the interview, such as how participant's described things e.g. their tone of voice. Whilst listening to the audio and reading the transcript a short summary was written of the participant's narrative to inform the pen portraits. This was followed by a close line-by-line analysis of each separate dialogue. Each participant's transcript was divided into three columns: the first was the raw data, the second was used for exploratory comments, and the third for emergent themes (see appendix X for example). For each line, analysis consisted of exploratory comments concerning descriptive (normal text) and linguistic (*italicised*) components of the text. Conceptual comments were also noted (<u>underlined</u>) to record the researcher's sense-making and inform the double-hermeneutic process. To identify emergent themes in the data, comments were colour coded according to the following factors:

1. Language – hesitant, repetition, tailing off, sighs, tone of voice (e.g. sarcastic, flat), use of humour, metaphors.
2. Phrases which expressed emotions or feelings.
3. HCPs interpretation of participant's perceptual anomalies.
4. Content of experience – their experience with perceptual anomalies.
5. Participant's sense-making of experience:

a. Related to ethnicity/culture
   b. Related to medical/psychological
   c. Related to religion/faith

6. Community sense-making of mental health and perceptual anomalies e.g. friends, family, extended relatives, neighbours.

Analysis developed from finalised single case analysis to multiple cases, where cross-case analysis of emergent themes was conducted (Smith et al., 2009). At this stage, areas of convergence and divergence in the participant's experiences were recorded. Subordinate themes across multiple cases were identified and then analysed to identity superordinate categories that captured these themes. At various points in this process, the analysis was shared with academic supervisors to further probe and validate the interpretation.

Initial categories were also discussed with a cultural consultant, who is a SA clinical psychologist working within the district the study was conducted in and the field of psychosis. This involved interrogation of the interpretation through reflective discussion, exploration of the transferability of the study findings and exploration of how study findings could be discussed at different levels: service user, EIS clinicians and service policy and development.

Chapter 4

- Results -

The following chapter will present the study findings. In-depth interviews were conducted with eight participants. Each participant's story provided a rich account of their lived experience of psychosis and how they made sense of it. Therefore an individual analysis is provided to illustrate the diversity and nuance of experiences. Each individual analysis starts with a pen portrait. The summaries do not form part of the analysis but are intended to provide the reader with a context. The individual analysis outlines super- and sub- ordinate themes for each participant, within which **text in bold** highlights salient themes used to help develop the group analysis. The final section of this chapter is an outline of the group analysis findings, where similarities and differences woven through these stories are discussed.

Individual Analysis

Ismail

"It just feels like it's just a canvas that's just painted grey, there's nothing there; there's no structure."

Ismail is in his early twenties; he is currently unemployed and living in the family home. He describes his relationships with his family as supportive but strained. Ismail wanted to impress his desire for and the importance of being in an intimate relationship, and this seems to continue to contribute to his difficulties of distinguishing between reality and fantasy. Along with this, Ismail describes hearing voices, that drive his beliefs that he is destined and capable of doing great things. He describes the ongoing challenge of not being able to trust others and not being able to *really know*, even now, if his experiences and perception of reality are true or not. There were times when it felt like Ismail was holding-back, and he noted he didn't want to say things that would be seen as being back in the *"danger zone"* by his EIS team. Establishing a chronology of events was difficult for Ismail, it was clear that some more extraordinary ideas and beliefs were alive to him in that moment and defining his immediate reality, and often his sense-making was tangled with these more

unusual beliefs and ideas. What strikes me about Ismail is the significant internal conflict he faces in identifying a 'truth' and 'reality'; he came across as someone who feels alone in his beliefs and ideas, and living with a deep sense of resignation in his efforts to gather evidence for and against his own sense of truth. The themes for Ismail are shown in Table 3.

Table 3. Superordinate themes and subthemes for Ismail

Main Theme	Subthemes
Struggling to define the experiences	
Reality as slippery	
The uncertainty of truth	Feeling overwhelmed and resigned to not knowing
Questioning illness beliefs	
Pervasive loss of power	A broken identity Hiding and being hidden

- **Struggling to define the experiences**

For Ismail, defining his experiences was elusive, and this was because its onset was insidious and novel, and to do with a fundamental part of himself and his perceptions of reality. He describes his reality as slowly ebbing away from him, and this impacting his sense of being. Although he used the label of psychosis, he reflected on its limitations in capturing his experiences, and it seemed to be adopted from his interactions with EIS.

> *"it's not like a usual illness. It's not … sometimes it doesn't feel like an illness. It feels like you've lost your mind. You don't really know what psychosis is. There's still a lot grey areas in it. It's like, you don't know what it is."*

- **Reality as slippery**

Ismail's perception of reality is slippery; parts are logical and stable even though contested by others. Therefore, his ideas and beliefs are not felt to be unusual or associated with an illness and the need for intervention. It seems that the perceptual anomalies are both a source of confusion and comfort. There is a sense of **powerfulness** associated with being part of God's plan, becoming a leader and telepathy. However, this is also terrifying and

disempowering, and associated with a loss of autonomy and being vulnerable to an outside force. The management of this is often a source of anxiety and distress. The nature of reality is also a point of contention between Ismail and his EIS team. Ismail feels that parts of his understanding of reality are not shared by his team, and this leads to self-censoring, despite Ismail holding these ideas with conviction. It seems that in this relationship there is also a sense of **disempowerment** and Ismail worries he's at the mercy of formal intervention.

> *"like I said, I, if I, if I say things in a certain way I'll become a concern all over again. I don't wanna bother with that…"*

- **The uncertainty of 'truth'**

For Ismail, there is uncertainty and doubt associated with establishing truth. There is a sense of deep **resignation** in the persistent internal conflict of identifying what is real and not. This leads to seeking external advice; however, this interpersonal dimension of establishing a truth generates its own sense of mistrust in not only his own appreciation of what's going on, but the intentions of others. The incongruence of Ismail's reality and that of others, leads to feeling rejected, lonely and disconnected from those around him. Perhaps most profoundly it leaves Ismail feeling **disempowered**, as he feels his reality does not align with that of his health care team.

> *"because you cannot define your reality from time to time you require people to define your reality for you and that's where it becomes, it can become abusive because you're in a situation where someone's telling you what's true and not true and what's the truth for you; what's not. And it might not be true"*

> o *Feeling overwhelmed and resigned to not knowing*

It appeared as though Ismail was **overwhelmed** by his experiences. There seemed to be a pervasive sense of resignation and persistent confusion associated with his experiences and attempting to understand why they were happening. It seemed as though Ismail was sinking under the pressure, and the effort of getting a handle on the meaning of his experiences. This was further compounded by Ismail's struggles to identify which experiences were related to "*the psychosis*" and which were *real*.

> *" I don't know what they mean um … I don't know [mumbles] I really do not know…
> umm . . . I don't know. It's just insane; this is insane"*

The overwhelming nature of identifying why he has these experiences, is also indicated in
Ismail's consideration of several potential explanations. He notes stress, morphine and
developmental factors, but does not seem to hold much stock in their impact. There is,
however, a clear sense that underlying his illness explanations is a feeling of being punished
and being 'done to', and a view that certain types of people experience psychosis.

> *"it's like I was a good person; I was like a good kid. I-I-I don't know what's happened
> to me . . .when it comes to psychosis"*

- **Questioning illness beliefs**

Ismail recalls initially rejecting the diagnosis of psychosis, and having an illness
understanding more in line with his spiritual and religious beliefs, but these too seemed to
be up for questioning, and Ismail notes his **beliefs changed over time**, and again there was a
sense of resignation in the instability of them. There seemed to be a circular confirmatory
process as part of this questioning. Here the perceived in/efficacy of different interventions
acted to confirm or disconfirm illness beliefs. For example, the effectiveness of prayer and
alternative help-seeking (religious homeopath) on his experience served to reinforce the
spiritual belief. Equally, the persistence of his perceptual anomalies and unusual ideas after
sectioning and formal intervention served to reinforce the idea that a pathologising
framework was not underlying his experiences.

- **Pervasive loss of power**

There was a real sense of the **pervasiveness of disempowerment** in Ismail's experiences,
not only via the perceptual anomalies themselves, but also due to the interpersonal
dynamics with family and in his interactions with formal services. Ismail's experiences with
family seems to have left him feeling silenced, unheard and overwhelmed. This appeared to
be mirrored in his interactions with HCPs, in terms of loss of power when under section,
feeling unable to challenge the beliefs of his EIS team for fear of repercussions, not feeling
like he has the power of refusal and feeling let down when he is not understood by his

team. Loss of power is also apparent in Ismail's reflections on the need to look to someone to help construct his reality, and also a consequence of the imposition of power when others construct his reality for him.

> "I'm not interested in my health team anymore. I'm just, I mean I cooperate with them because the doctor says it's called concession [compulsory?] where you just have to."

- *A broken identity*

Not feeling in control has also had a profound effect on Ismail's **sense of identity**. It seems to have become fractured, and there is grief associated with the loss of who he was. His current identity is associated with being in deficit, things not working as they did before, and not being the same person with the same potential anymore. A broken identity is also related to Ismail's enduring sense of otherness and the loneliness that comes with not feeling like he is a part of his community as he is now separated from them by his experiences. The loneliness seemed to be both a precursor and a consequence of his unusual experiences.

- *Hiding and being hidden*

Secrecy regarding MH difficulties seemed quite familiar to Ismail, and described as a common practice in his wider family and general community. In this respect it appears that Ismail was **hiding and being kept hidden**, and the family acted in a protective but isolating manner. This protective isolation was perhaps two-fold: for Ismail it seemed a way to mitigate the disempowerment that came with sharing his unusual ideas and beliefs with others; for his family it seemed a way to avoid the risk of **shame and stigma** associated with MH difficulties, and detrimental impact on one's reputation in the community.

> "it affects you a lot, cause it does, because when we get married and settle down and you have to build up credibility and you can't do that because obviously you're getting sectioned left, right and centre and er, whenever"

Sirah

"I'm really glad that happened cause I really never thought about my mental health that much, to be honest. Cause I didn't even know like umm, doctors help with mental illnesses."

Sirah is in her early twenties, currently living at home with her family. Approximately three years ago, Sirah left her job as she experienced a period of high stress, poor sleep and loss of appetite. She spent a lot of time at home and became increasingly worried about leaving her house. She began to feel like she was being watched and felt unsafe amongst strangers. This led to withdrawing both from the outside world and her family and Sirah struggled to take care of herself. Sirah was confused by her experiences and worried about sharing her thoughts and feelings with her family. She described not seeking help straightaway, because she and those around her didn't realise she was experiencing MH difficulties. Although Sirah described her experiences as not very severe, a continued decline in her MH led to requiring inpatient support on two occasions, both initiated by her family. Despite the challenging nature of her experiences Sirah viewed them as transformative and a journey of self-discovery and learning. Sirah was keen to share that she is currently working and considers herself recovered from psychosis. The themes for Sirah are shown in Table 4.

Table 4. Superordinate themes for Sirah

Main Themes
Unfamiliar experiences
Down-playing, self-censoring and stigma
An assimilated health and spiritual explanatory framework
Reclaiming identity and positive change

- **Unfamiliar experiences**

Sirah had a strange experience of being watched and feeling in danger soon after leaving her job. She kept this to herself and became increasingly worried, leading to irritability and withdrawing from her family. She described feeling listless, not herself anymore and ruminating on what will become of her. She hadn't experienced anything like this before and found it difficult to pinpoint what was happening. Her experiences were considered a physical health symptom by herself and family, and this seemed to be more acceptable and

familiar territory. Sirah notes she wasn't aware of a term for her experiences until after her interactions with EIS.

> *P: er, yeah, I like umm, I don't know. Like umm, I didn't think it was a mental health problem; just thought it was like umm, I didn't want them to think umm . . . I don't know. Like umm. . . I don't know why umm*
>
> *I: mmm*
>
> *P: umm, when I was feeling paranoid, I didn't even know at the time I was feeling paranoid. If you get what I mean*
>
> *I: yeah. Okay*
>
> *P: afterwards I found out it was paranoid. I didn't even know myself I was being paranoid. So, I couldn't go to them like if you get what I mean*
>
> *I: mmm. Yeah*
>
> *P: cause I didn't know myself, huh!*

- **Downplaying, self-censoring and stigma**

During the interview, it seemed as though Sirah downplayed the severity of her difficulties (*"then I started becoming a bit paranoid"*/*"but I think mine wasn't that severe"*/ *"It was just like I was feeling a bit sadder"),* despite them leading to two inpatient admissions. Perhaps there is a temporal element, in that some of these experiences felt short-lived and Sirah considers herself recovered from them (*"it's like my brain like stopped working for a bit"*). However, there was also a sense that Sirah had downplayed her experiences at the time, in an effort to manage her outward appearance and avoid potential **shame and stigma**.

> *"I just said, oh umm. . . like I don't feel very happy and . . . umm, like umm, I feel really tired and things like that"*

A risk of stigma is also echoed in Sirah's reflections regarding poor community education and awareness of MH difficulties. A fear of being dismissed and becoming part of community gossip led to hiding difficulties, or reframing them so they are more acceptable and not associated with a chronic problem.

- **An assimilated health and spiritual explanatory framework**

Although Sirah considered her experiences in the context of migraines and difficulty breathing, indicating a health interpretation, she also understood some of her experiences were a result of "*nazar*" which she translated as 'evil eye'. Nazar was described as when someone else is jealous of a person, they can cause illness in that person, which was a common belief held in her community. Sirah explained that low mood, depression and feeling out of sorts is a common effect of nazar, all of which she had experienced. She also felt there was a health explanation for her paranoia, provided by EIS. Both frameworks seem to have been assimilated to explain different experiences. Belief in each of the models was reinforced by **testing and proof**. For nazar, rituals and external validation via an Imam provided support; and for the health model internet research and professional opinion reinforced the framework.

> *P: Put chillies under like gas, on the tavar[5] and stuff and then if there's a smell comes, if you can smell something, that means umm, that er, there's no nazar, and if you can't smell something, that means there is*
> *I: mmm*
> *P: yeah. Like no smell came so it was true*

> *"they just said I had psychosis like when you think things are happening and they're not really happening and you're a bit paranoid and I go, 'oh, is that why I've been like that?', yeah"*

There seemed to be comfort associated with the knowledge that nazar is curable, and under a spiritual framework of illness, difficulties are not chronic and can be prevented or cured via prayer. Comfort and conviction also came from the illness belief being in line with Sirah's faith and ontology ("*oh it's just in the hands of God. Like I'm not afraid. I just look to God."*). An assimilated system of illness explanations seemed to allow Sirah to maintain an innate understanding of illness alongside a new framework regarding MH. This meant that she

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[5] "*tavar*" refers to a flat cooking plate.

could share her experiences under some common language used in formal services. However, despite the spiritual model appearing more deeply embedded, it was not something Sirah felt comfortable sharing with HCPs.

> *"umm, I didn't with the staff. No, er, like everyone's got different beliefs so er, umm, I think most of the staff there were like predominantly White so, I don't know if they believed in it or not. That's why I didn't talk about it like that yeah, so, we've all got different beliefs, so I don't know if they believe in it or not. That's why I didn't talk about it."*

> *"but I did share other stuff about stress and normal stuff but not like my religious beliefs and that because obviously they have different religious beliefs. I didn't mind sharing it. Like I'm not like shy. Like if they ask about something, I'd say I wouldn't tell them without them asking"*

Sirah's reflection here suggests she was open to talking about her beliefs but would not self-initiate this. Framing her illness models as related to "*stress and normal stuff*" as opposed to religious beliefs indicates that the latter was perceived as different or the alternative to a mainstream explanatory model.

- **Reclaiming identity and positive change**

Sirah's experience seems to be divided between losing her identity and then reclaiming it as part of her recovery. She characterised herself as being different, "*unwell*" and having a "*condition*" , which was associated with losing her role in the family. Conversely, she feels she is now recovered, and associates this with regaining her sense of self, her roles and being employed. This reclamation was also associated with Sirah's experience of a process of change and **positive transformation of herself**, including learning about her MH, seeing herself as more independent and resilient, and someone who has matured and become stronger as a result of her unusual experiences.

> *"so, before like it happened, I was like, everything was normal like umm, er, like I were a strong person, but I think like now I'm even stronger, but I remember during I was quite weak and upset"*

Asim

"Like I said about culture. You don't talk about mental health."

Asim is nineteen years old, the oldest of four children, all currently living in the family home. Asim described a difficult and lonely childhood, he was bullied up to his teen years, and found making friends in a predominately White school very difficult. He started to hear voices in primary school; describing them as "*self-talk*" but perceiving this inner speech dialogue as external to himself. In his early teens, Asim was given a diagnosis of 'clinical depression', and he often self-medicated with cannabis. As Asim grew older, he started to hear multiple voices, starting off as commentary but over time the voices became either malevolent, commanding and threatening; or soft in tone, patronising and belittling, which drove his experience of "*non-stop paranoia*". Asim spoke of a spiritual element to his perceptual anomalies, of sensing, hearing and communicating with Jinns, an experience he sometimes shared with his best friend. He spoke candidly about the impact of his ethnicity, religion and culture on his identity and unusual experiences. He continues to hear voices which have returned to being neutral commentary, and frames this as "*just my mind talking to my mind!*". The themes for Asim are shown in Table 5.

Table 5. Superordinate themes for Asim

Main Themes
Alone with the voices
The frustration of feeling silenced
Not belonging and identity
Finding a place between two explanations

- **Alone with the voices**

Asim's voice hearing started in early childhood, and this seemed to be a form of companionship, and a way for Asim to cope with the rejection and disconnection from his family, community and peers. Past and present experiences are linked by social isolation and trauma. As a young person this was via the persistent racially motivated bullying and

more recently via the nature of his experiences of hearing maleficent voices, seeing and sensing Jinns.

> *"Yeah. I remember being a kid like in primary school. Sat on the carpet … hearing voices. […] So after being bullied as a little kid and I'd be bullied in school. And then also outside of school wherever I was, then I'd be bullied then as well. And a lot of it was racism. Erm I went to a school that was predominantly White. So being the 'Paki' erm … wasn't really … helpful."*

Perceiving the voices as company was a positive experience for Asim, and something that did not initially cause much distress. A familiarity with the voices meant that Asim came to believe it was an idiosyncratic way of thinking. He felt he had control over the voices initially, but as they changed from commentary to commanding, and he began to associate them with the presence of Jinns, he felt increasingly overpowered by them. Feeling alone was amplified by the changes in content and tone of the voices driving Asim's feelings of being watched and judged by others. Isolation was initiated by Asim, cutting all but one friend out to protect himself, but was also driven by others. He recalls his family's decision to move his siblings into his aunt's house when he was unwell, as they did not think it was appropriate for them to be around their brother. Interestingly, Asim felt this was a reasonable action. There was an overwhelming loneliness in the way he coped (smoking cannabis alone), and the rejection in his attempts to share his growing sense of unease. When formal intervention was initiated by his best friend, Asim felt frustrated and resented it as *too little too late* and felt disconnected from what was happening by that point.

> *"Erm … I was in a, I was just too in my own place. I was in my own bubble to even … really, I think I was in the room with the doctors and I just didn't care! Erm … there was concern from every other person but I'd stopped caring, because it always seemed like nobody else cared. So now that everyone else is concerned, why should I be? See how it feels! Only when you … when you're the one that's worried and not getting anywhere, not getting anything back!"*

- **The frustration of feeling silenced**

Feeling silenced extended beyond the experiences of voice hearing and feeling watched, and Asim described that it was very common for him to **hide things from his family** (such as drug use to cope or having girlfriends), because he *knew* there would be repercussions and risk of bringing dishonour to the family. This seemed deeply frustrating for Asim, as he felt the family values of respect and honour superseded being open.

> *"No. So for example extended family erm … so my … erm … my second cousins? They didn't know. They still don't know a thing about my mental health! They don't even know that I've been struggling with depression because it's frowned upon to talk about! That's just! That's fucked like!"*

The impact of feeling **silenced and disempowered within the family and community**, and this being somewhat of the norm, acted to shut down Asim's emotional openness, a change from how he initially felt. He notes that family often interpreted his openness about MH difficulties (his own and generally) as a sign of being unwell. This suggests those around him perhaps had a limited understanding of MH issues, and there was a deeply engrained **stigma** associated with it.

> *"Erm … Yeah so my family's learnt to understand mental health but still … brush it under the carpet! […] P: Like … Like what am I supposed to do when I need help? Am I going to go to you and say oh I need help, this is going on? Or am I supposed to act as if it's not happening?"*

There seemed to be a lot of **power held by the community over the family** in determining reactions and responses to MH difficulties, leaving Asim in a position of **disempowerment** in his interactions with them and in his attempts at being open about MH being dismissed and going unheard. The pressure to adhere to cultural norms created confusion and conflict about how to behave and where to seek help.

- **Not belonging and identity**

Asim sees himself in a conservative and close-knit community due to his heritage, and also Western society, where he has grown up and been educated. He describes feeling like being

a part of but not *really* belonging to two dissimilar cultures has created a sense of **detachment from both identities** and some conflict between them. Experiencing MH difficulties and gender stereotypes held by those around him, also seemed to have an impact on the way he feels his identity is regarded by others.

> *"Erm yeah so. I, the male side of the culture. It's like you know you've got to be, you've got to be strong. You've got to be honourable. You've got to respect your family. Erm … You've always, you've got to be the confident person. You've got to be in charge. Erm … can't really show weakness when it comes to … mental capacity. And you can't have erm … yeah you can't be vulnerable in that sense. Yeah."*

- **Finding a place between two explanations**

It appears as though Asim held two explanations for his FEP experiences but struggled to find where he fitted between them. Part of his understanding was under a pathologising framework where his experiences were felt to be a culmination and interaction of several factors, including early childhood trauma, depression, bipolar, anxiety, stress induced MH difficulties and cannabis use. This explanation seems to be derived from his interactions with various MH services and there appears to be an element of respect for the clinical perspective. However, there also appears to be quite a lot of **power assigned to this clinical voice**, even though it is in the presence of another belief, related to spirituality.

> *I: Yeah. So have you had any experiences where someone has said that "I think, or we think really this is what's going on." And you're like "No that's not my…"*
> **P: Yeah. But I don't mention it to them because it, there's no point arguing. […] The thing is like whenever they say something I don't argue with it because there's no point! Because … you know they're the ones with the, with the qualifications. With the degree. With the whatever! With the power yeah. They're the ones with the power and the, they're the ones that will decide your future when it comes to medication you're taking, the people that you're talking to. If you say no I really don't think that's the case. It's like 'oh well now I'm going to have to go back to square one! Because you opened your mouth'!"**

Despite Asim assigning some truth to a health model, he also seemed to feel resigned to it, as he perceived consequences of having and sharing a different explanation. He described feeling like the MH team would not appreciate in any way what he thinks and there is risk associated with sharing a spiritual model and it being perceived as a sign of illness. This seems to have resulted in Asim actively managing what he shares with others regarding his beliefs related to a spiritual explanation of Jinns, despite this being an embedded framework. It seems that Asim is pulled between two beliefs and it is his role to assimilate the models and find a place where he belongs within them. For Asim this assimilation involves a recursive process of identifying which experiences are a result of psychosis and which are spiritual and *real*. Some of this is via shared experiences with his best friend or via seeking external validation from religious scholars.

> *"And I've told him about the experience with Jinns. Sometimes he was there! When I, like when the Jinns were there and he'd like feel it as well. So that's how I knew it wasn't always erm … psychosis or something else. I knew part of it was real. Part of it, yeah, is real."*

Nazreen

> *"I thought okay it could be my physical health and then I thought it could be something spiritual. Like I was confused"*

Nazreen is nineteen, the youngest of three, and lives at home with her parents and siblings. She describes having an underlying condition of bipolar disorder and going through "*a phase of psychosis*". Nazreen recalls her experiences began with a sense that she was losing touch with reality and she couldn't trust those around her. She describes seeing eyes floating above her and having conversations with someone no one else could see. At first this made Nazreen feel powerful, but as the unusual experiences persisted, she became more and more terrified and confused. It was clear during the interview that Nazreen's experiences had a significant impact on her. I was very grateful to her for sharing them, and engaging with me, in the presence of the strong emotional effects of recounting them. Nazreen was keen to impress she no longer experiences psychosis, but accepts she has MH difficulties and continues to successfully manage experiencing bipolar disorder with the help of

medication. She believes her experiences have shaped who she is now, and have in some ways been transformational; allowing her to become a stronger, more mature person than she was before. The themes for Nazreen are shown in Table 6.

Table 6. Superordinate and subthemes for Nazreen

Main Theme	Subthemes
Feeling disconnected being double edged	Managing stigma and shame
No one could understand	
Trying to find a way out of competing explanations	

- **Feeling disconnected being double edged**

The most salient experience for Nazreen was feeling disconnected from everyone and this driving a belief that she was in danger. The detached feeling cut both ways, being both lonely and "*terrifying*" but also making Nazreen feel **powerful** and "*good"*, believing she was a *"genius"* and enjoying having *"a special power to talk to people"*. However, as Nazreen came to realise that these experiences were not shared or reinforced by those around her, her appraisal changed, and she associated her beliefs and perceptual anomalies with being unwell and abnormal. Her experiences became more scary and confusing, and Nazreen struggled to find a way to share what was happening.

> *"That's the thing! It's really hard to speak up when you don't even know what you're going through yourself. Like even if I did speak up, what would I say?"*

o **Managing stigma and shame**

It appears as though some disconnection was deliberate, and Nazreen recalls withdrawing to protect herself from further peer rejection and the **risk of stigma** associated with MH difficulties. She was comforted in the knowledge that her family are not particularly religious or embedded in the community, as this helped alleviate any sense of pressure to adhere to cultural or religious norms. She worried and feared others finding out about her experiences, however there appeared to be ways to mitigate the risk of social stigma, **by**

hiding difficulties and sharing elements of them that seemed more socially acceptable, for example low mood.

- **No one could understand**

There seemed to be a lot of frustration in trying to establish an intersubjective understanding, and that appears to be related to the idiosyncratic nature of the experiences but also the incongruence of initial illness explanations between Nazreen and others, resulting in several months of repeated visits to the GP. This led to Nazreen feeling quite hopeless and resigned in her efforts to get people to understand what she was experiencing. Interestingly, despite this, Nazreen followed all of the advice provided by the HCPs, indicating a level of **power in the voice of a professional.**

> *P: And no one would understand like how I felt. No matter how much I explained it to anyone!*
> *I: Okay.*
> *P: Cos obviously they're not going through it. It was me going through it.*

- **Trying to find a way out of competing explanations**

Nazreen described two illness beliefs related to her unusual experiences: a health-related explanation, provided by EIS, regarding a psychobiosocial interaction that triggered psychosis; and "*nazar*", a common belief held in her culture. Nazreen described nazar as 'evil eye', which she defined as jealous people causing illness in others. However, she seemed hesitant and embarrassed to provide further thoughts regarding this explanation.

> *P: Yeah like em … in our religion we believe in like some spiritual things that can happen.*
> *I: Okay.*
> *P: So em … yes he thought it could have been that. Yes I don't want to talk about that.*
> *I: Can I ask if you thought that was happening?*
> *P: Yeah at one point I thought what if it is?*
> *I: Okay.*

P: Em and I overcame that. I knew it wasn't that cos it was something else. Definitely, yeah.

The health model is described as a more "*rational*" and "*logical*" framework, whereas "*nazar*" is referred to as the alternative, more "*irrational*"/ "*emotional*"/ "*uneducated*" way of thinking about illness. It appears as though the acceptance or rejection of a model also reflects the character of the person. Nazreen describes her father holding a health model and being a more logical person, whereas her mother holds a spiritual model and is described as *"not as logical"*. This seemed to create an inner turmoil and confusion about which illness model to hold and Nazreen used external validation to help make a decision about what to believe. The confusion was further compounded by the nature of her experiences.

> *"Because first I thought, em, first I thought yes something's wrong with me. What is it? And then I thought okay it could be my physical health and then I thought it could be something spiritual. Like I was confused. And I was, already confused like with the psychosis. And I was even more confused trying to figure out what it was. So it was just so confusing."*

There is a sense that it has to be one or the other, even though it seems that initially, Nazreen held a centre position, and felt it could be both. Perhaps as a result of an attempt to reduce the sense of confusion and due to the connotations associated with "*nazar*", Nazreen appears to ultimately reject this model, in favour of a health explanation. Illness belief also appears to be related to perceived efficacy of intervention. As Nazreen feels medication is working, it seems to increase her conviction in a health illness model.

> *I: Yes. Definitely. And I guess initially when we spoke you said there could be a spiritual element and a medical element. What do you believe now? Do you think it can be both still or em?*
>
> *P: No I, I truly believe that's mental health.*
>
> *I: Can you think why that might be?*
>
> *P: Because I literally, as soon as I took the medication, I just got better straight away.*

Salma

"I was like, you know I'm not gonna get help that I need and, because number one obviously like mental health is such a taboo in Asian communities […] and I don't know about other communities but in the Pakistani community, it doesn't exist. So, um, if you're depressed, it doesn't exist. If you've got anxiety, it doesn't exist. If you've got mental health issues, it doesn't exist."

Salma is just into her forties and lives alone. The last 20 years have been very challenging for her, and she describes over this time leaving an abusive marriage and being ostracized from her family and community as a result. After the separation, Salma felt like she had to rebuild her life from scratch and found she went into being on *"autopilot mode"* and *"faking it, to make it"*. Around five years ago, Salma thought she heard the voice of her ex-husband, whilst at work, provoking a lot of anxiety and worry. This quickly escalated into the voices of strangers making derogatory, *"perverted"* comments and commands to harm or kill herself. It has since snowballed into blackouts and seeing things which terrify her, such as a *"churel"* (witch) wrapped around the pillar at work and a traditionally dressed Muslim man who follows her around (present during the interview). Salma has become frightened to leave home and engages in certain religious rituals to protect herself when she has to. Salma's story holds a powerful narrative of the self as both fragile and resilient. Despite the intensity of her experiences, Salma continues to advocate for herself, and retain employment. She has left a deep impression on me, having been through so much with little support. I was struck by her strength to keep going and trying to live a fulfilled life and not seeing herself as a victim but as a survivor. I really enjoyed meeting Salma, and I hope I can do justice to her story.

> *"I'm hoping that obviously with me taking part in this study for yourself, your thesis open the eyes of the Asian people and they get in the sense that stop treating it like it's . . . it doesn't exist. I want them to acknowledge it. […] The last thing they need for you to do is to make them feel like that they are not normal"*

The themes for Salma are shown in Table 7.

Table 7. Superordinate and subthemes for Salma

Main Theme	Subthemes
Fighting to maintain normality	
Wrestling with power and control	Being controlled The location of power Disempowerment of Salma's voice Loneliness and rejection
Wrestling with illness beliefs – black magic/possession vs. PTSD	
Testing and proof of illness beliefs	

- **Fighting to maintain normality**

Salma's perceptual anomalies are characterised by an intense and overwhelming sense of fear and confusion. It was perhaps felt more acutely because Salma had built up another persona of someone who is strong, confident, resilient and in control of her own life. This 'new Salma', was different to the 'old Salma' who was a victim of violence, and was vulnerable. But this new sense of self was fragile, and Salma spoke of how exhausting maintaining this façade was and no longer *really* knowing who she truly is. She did not want to risk being judged or perceived as abnormal, and there seems to be a real fight to maintain the guise of normality, with careful consideration being given to each action or word.

> "There's days, like even today, like I literally am hanging on by the tip of my fingers just to have a normal life; to, to have a normal day"

- **Wrestling with power and control**

  o *Being controlled*

Both past experiences and current perceptual anomalies can be characterised by being controlled by someone or something. Initially, it was Salma's family, then her ex-husband, and now the voices. These experiences have left Salma feeling like her grasp on her own autonomy is tenuous, and is something that can be easily manipulated and taken away. The

strength of her conviction of the control of the voices/entity is indicated in Salma's almost total social withdrawal, due to the fear it will do something to her or through her.

> *"And then, then at times it used to be like cause if I didn't have any control over my body and I used to take every, every strength that I had to just stay stood where I'm stood"*

- o The location of power

In the same way that Salma felt her grasp on her autonomy was tenuous, it also seemed to be the case for her sense of power. Power appeared to be something Salma located externally to herself, and something that is negotiated with others. It was clear from Salma's discussion of her attempts and experiences of help-seeking that she gave a lot of **power to the voice and opinions of HCPs**. Sometimes this was intentional as she was looking to the 'expert' to construct her reality. Sometimes this was involuntary and it appeared to be out of desperation to make sense of her experiences and part of a cultural value of placing one's faith in doctors and qualified professionals (*"so, I was like, again, he's a professional, he would know").* Each time Salma was given an external explanation or diagnosis and intervention, she adopted this and adhered almost without question. Here Salma refers to a counsellor she was seeing:

> *"I became like at his mercy kind of thing"*

- o Disempowerment of Salma's voice

A consequence of this was that Salma felt power is something that can easily be taken away. She worried and feared that openness about voice hearing would inevitably lead to sectioning and hospitalisation, and was therefore cautious about what she disclosed. Salma also described her experiences of help-seeking in the context of feeling let down, dismissed and not heard. This was regarding both domestic violence and voice hearing experiences. For the latter, Salma recalls her experiences being dismissed under a common MH condition. Salma reflects here on the impact of the ethnicity of her GP and described returning with a rehearsed script to receive the support she needed.

> *"and er, again, the GP being an Asian doctor, he went, 'Oh okay. You're depressed'"*

Ethnicity and help-seeking was also discussed in the context of her work with EIS. Although she positively appraised the openness of her care coordinator (who is White) when she shared her illness beliefs, there seemed to be an unspoken understanding that this is something she can explore outside of formal intervention. Salma notes that having a similar ethnic background as some of her HCPs, has been a positive experience and allowed for a more nuanced understanding of her experiences and a more active approach to interventions in line with her primary illness belief. It appears as though this allowed for Salma to feel her voice was being heard.

> *P: because er, it's like when I was telling him about the religious stuff that I was doing, and he, because obviously he, being a Muslim man, he knew what I was saying and so it was a lot easier for me to explain it to him than it is for me to explain it to like, for example, [care coordinator] because when he, it's not like he didn't understand, he did, but it was just that thing where if I said, 'Oh I did this' and he'd, [EIS staff member] would be like, 'Yeah, I know,' you know he did this. You know what don't do that, try this now'*
>
> *I: what was he recommending?*
>
> *P: so, he gave me some like little verses from the Quran to read. They're like small little verses and er, he was like, you know read this, you know after you've read your prayer, re-read this, and er, see how that does it.*

- o Loneliness and rejection

What resonated throughout Salma's story was a profound sense of loneliness due to the systemic rejection from others, including her family, the wider community, her work and from Salma's interactions with various HCPs over the course of her experiences to date. The social rejection from her family was centred around family and cultural norms regarding "*izzat*" (which she translated as family honour/respect/reputation), and the impact this had on the wider community perceptions of the family.

> *P: and er, they're going to talk and er, basically I have brought shame on the family and I shouldn't be telling anyone'*
>
> *I: mmm*

> *P: you know, 'If she's hearing voices why doesn't she just stay at home in the house; why doesn't she stay indoors and not interact with anyone'*

It appears that the **community held a lot of power over the family**, and the subsequent response to Salma's difficulties in terms of silencing rather than supporting (*"That's how I felt. I felt like they'd outcasted me"*). For Salma this greatly reduced her confidence in sharing her feelings, to avoid further rejection and become part of the rumour mill. There is a sense of a storm of emotions of anger, frustration, sadness and disappointment at the reaction of others to her difficulties, and where this left her.

Social rejection appeared to stem from a limited understanding of MH issues within Salma's family and wider community. Her work colleagues rejected her as someone to be frightened of and Salma describes that her family commonly attributed her experiences to a personal failure (hers and her mother's), lack of effort to be happy, or infantilised as going through a phase and attention seeking behaviour. Salma's social withdrawal, and choosing to no longer speak to her family about her voice hearing, served to reinforce these ideas. A poorer understanding of MH seemed to stem from its abstract nature and, as something intangible, it appeared to lose its credibility as an authentic concept and difficulty.

> *"that's what he said, 'I can't see it. So, how am I supposed to believe you've got it? 'But when she's saying this stuff like oh, she's depressed, and she's got mental health issues and I can't see that so,' he goes, 'I don't believe it,' So to me he goes basically, 'She's just acting'"*

- **Wrestling with illness beliefs – black magic/possession vs. PTSD**

Salma described two illness models. One appeared to be a dominant framework of understanding and related to black magic and possession by a "*Jinn*" (entity).

> *P: well, what I thought was happening was nothing related to mental health*
> I: mm
> *P: it was more related to black magic*
> I: can you explain

> *P: you know basically, there was this man that er, in that same time of because of how I connected it to that, was the same time when the voices started, I had an altercation with a religious spiritual leader.*

Salma describes that within this spiritual explanation, MH difficulties are preventative and curable, and perhaps this also serves to strengthen conviction in it. For Salma, this belief and her strong faith are protective factors and a great source of comfort, and formal intervention is therefore a secondary help-seeking route.

> *"It's this, this is what's, the religious perspective is what's going to cure it, what's going to get rid of it; what's going to get rid of the voice that I hear and then if anything happens after that, then we can look at it from the mental health perspective."*

The alternative understanding of her experiences comes from her interactions with her EIS team. Salma described that they felt the voice hearing was likely related to repressed emotions associated with her experiences of extreme domestic violence resulting in Post-traumatic Stress Disorder, and the stress induced from altercations with her father. However, the addition of this secondary model seems to have resulted in Salma **wrestling** between them, and it seems that conviction in each model varies depending on the context she is in. Even though there is a primary illness belief related to black magic and possession, this was perceived as "other", compared to the more dominant pathologising framework, and Salma described a division in the responsibility to make sense of each belief between herself and EIS.

> *P: and so, it was like I said er, previously, I was stuck between is it a religious thing*
> *I: mm*
> *P: is it, is it this demons or whatever, or is it actually a mental health thing; is it me hearing voices.*

The juggling between two illness beliefs also led to a sense of confusion as to which intervention to undertake, and if one could possibly exacerbate illness, if it was the incorrect route.

- **Testing and proof of illness beliefs**

A consequence of this wrestling and prior experiences has left Salma sceptical of both explanations to some degree. She describes quickly moving between trusting and doubting each model and their proponents. Salma described a recursive process of **testing and identifying proof** for each explanation. However, this appeared disproportionately greater for the spiritual interpretation. This was indicated by a Google search of the EIS explanation, but a more systematic process of exploration of the spiritual explanation via deconstruction of unusual experiences (e.g. what the voice is saying, marks on her body) and receiving external validation from family and several *"religious scholars"*. This, along with perceived inefficacy of antipsychotic medication and efficacy of the rituals in stopping the voice (albeit temporarily), served to act in a self-confirmatory manner, and reinforce Salma's explanation of black magic and possession.

Dalil

"It's just I feel I'm just sort of spiralling out of control in some way. Like they're trying to take over my life and I don't know who to turn to or what to turn to. I don't know who can make this problem go away, of hearing voices"

Dalil first heard voices as a very young child and interpreted them as a normal form of companionship. The voices became more prominent around the age of nine, following a serious trauma. He is now in his late twenties and currently living with his partner. He has recently spent time in hospital, under an involuntary section, where he was told he was *"schizophrenic"*, although Dalil, does not hold much stock in this. He has had a very challenging life, including feeling neglected by his parents, childhood sexual abuse and a forensic and drug history. Dalil finds the voices oscillate between malevolent and commanding (to harm himself and others) or benevolent, protective and advisory. They often reinforce his grandiose ideas and beliefs of becoming a leader and multimillionaire. Initially, Dalil was able to exert some direct control over the voices; however, over time, this seems to have reversed and he now feels the voices exert control over him. Although less frequent, Dalil also experiences visual perceptual anomalies of strangers, Jinns and angels. It is clear Dalil tries his hardest to manage them, but continues to find them overwhelming

and "*unchallengeable*". Dalil's life seems very lonely, and he describes feeling rejected from his family and community. He described his perceptual anomalies as continuing to be a part of his everyday life, and he uses prayer and the support of his partner to help manage them as best he can.

There were points in the interview when Dalil seemed to lose attention, become less coherent or express his thoughts and beliefs in an unusual way that I could not understand. He did not go into much detail about how he had made sense of his experiences, and I wondered if that was because Dalil was still living with his perceptual anomalies, and thus wasn't quite ready to reflect on them. This interview felt a little bit more disjointed, but I think we both enjoyed the process. The themes for Dalil are shown in Table 8.

> **P: I think that's everything covered, I think. I'm just grateful that you made me start to have a conversation with you. You're a very nice person**
>
> *I: oh, I'm very grateful that you've been so open and generous with your story about your experiences. And I really do. . .*
>
> **P: …that's okay**
>
> *I: thank you*
>
> **P: I've had a good time so, I appreciate you very much Krisna**
>
> *I: oh, thank you very much.*

Table 8. Superordinate themes for Dalil

Main Theme
An ambivalent relationship with the voices
Pervasive rejection
An elusive understanding

- **An ambivalent relationship with the voices**

Dalil seems to have a complex relationship with his voices, that has developed over many years. Despite a familiarity, he describes knowing this made him "*not really a normal person*" and "s*omeone out of the ordinary*". Feeling different has been exacerbated by Dalil's interactions with others who also view him as such. The voices appear to have

become more prominent after each of Dalil's trauma experiences. They were initially positively appraised as they appeared to be a form of protection, comfort and company when Dalil felt most alone. It seems as though Dalil felt he was able to exert control over the voices, regarding when he wanted to engage with them. However, this seems to have changed over time, and it seems now Dalil has lost control over them and they have become "*very, very unchallengeable*". They are now perceived to be omnipresent and have **power over** Dalil. Because the voices have become both malevolent and benevolent in nature; protecting Dalil from harm but also commanding him to harm, Dalil has lost his sense of autonomy and the relationship has become confusing. This confusion is echoed in Dalil's sense that the voices can sometimes drive his more grandiose ideas and beliefs and are therefore capable of manipulating him into illegal activities, but sometimes his ideas and beliefs come from him and are achievable.

> "*you don't know what they're actually here for. They could be here for a reason. They could be here to destroy me or protect me. I don't know which one it is yet [sniffs]*"

Dalil feels he needs to continue to try and engage with and understand the purpose of the voices, to almost renew the type of relationship they have, and protect himself from the power they hold over him.

> "*I need to speak with my voices, because you know I need to understand them because if I don't understand them, they could either get offended or take action towards me somehow and get worser by talking in different manner*"

- **Pervasive rejection**

For Dalil, there appeared to be a pervasive experience of rejection, by his family and the wider Bangladeshi community, and perhaps also self-rejection. This seemed a fairly consistent experience across his lifespan. Both **systems seem to hold power** in how Dalil perceives himself, and how he and others understand his difficulties. Rejection was related to the general negative connotations associated with MH difficulties but, for Dalil, this was superseded by his forensic and drug history. There was a sense of others dismissing or disbelieving trauma experiences and difficulties. For Dalil it seemed that there existed the **double stigma** of voice hearing and a drug history, and therefore an increased risk of social

rejection and being ostracised by his family and wider community. Dalil described this in the context of several interpretations and reactions the community held regarding his difficulties, including personal failure, punishment for poor behaviour/drug use, a way for Dalil to manipulate others or under a spiritual framework (Jinns).

> *"the fact that I'm brown in skin colour when it comes to these sort of situations where-where like we're demonizes, people who deal with things like drugs and guns, and that we do bad things, that we bring bad on ourselves and stuff. So, that was the general notion in the community that you brought it on yourselves so there's no one that can help you."*

There appears to be a sense of **conflict in identity**, which is influenced by family and community perceptions. Dalil discusses the difficulties and the frustration of belonging to the Bangladeshi community and his desire for acculturation, and the impact of this on his self-acceptance and help-seeking.

> *P: oh, my parents are back minded, huh! They're, they're very back minded, huh!*
> *I: what do you mean*
> *P: they're like "don't get involved with White people; don't get involved with social workers. Don't go to people about your problems and stuff like that. It's disrespect to the family or we don't want to know you if you do go to these people"*

- **An elusive understanding**

Identifying an understanding remains elusive for Dalil. It seems as though the focus on the power and intentions of the voices, leaves little room to step outside of these experiences to make sense of them. This is illustrated in my attempts to elicit Dalil's explanations for his experiences.

> *"I dunno. I just, I can't explain that side of things cause I don't know myself to be honest. So, I couldn't give you an explanation"*

> *"I dunno. It's just, there's something unexplainable, to be honest"*

Where Dalil did share his thoughts on beliefs, they seemed tentative and difficult to shape into a framework of understanding. One illness belief referred to black magic, which Dalil feels he was exposed to as part of his forensic and drug experiences. Although he questioned the validity of this, he sought external validation from his Imam, who confirmed black magic, but was unwilling to support further due to Dalil's drug use. It seems that rejection of support, the Imam locating the problem in Dalil, and the resignation he associates with this illness belief led to a cycle of continued drug use.

> **P: what happens is when you're selling drugs, you do black magic on people, so they don't become your enemies so, you can keep them at bay. And people used to do that and then someone did it on me and I don't know if it's true or not but that's when I started hearing voices**
>
> *I: right*
>
> **P: I believe it could have something to do with it**
>
> *"I was like, you know it's black magic I can't take it off me so it's gonna stay with me forever so, I might as well stay on drugs"*

During his interactions with HCPs Dalil recalls receiving a diagnosis of schizophrenia and drug induced illness, but it does not seem to be something he has accepted as an illness model. Perhaps he is sceptical here because he separates his visual anomalies as occurring under the influence of drugs, from the voices which first started in childhood and persist with and without drugs.

> **P: it just didn't like seem to add up, because so what if I was smoking cannabis it doesn't mean that I'm hearing voices. Even when I'm not taking cannabis I'm hearing voices so, that's why I knew that they wasn't always like on the same path as me of understanding**
>
> *I: right. And what do you think it was then if it wasn't the cannabis and the drugs?*
>
> **P: I don't know. That's what I couldn't really explain. I'm sorry. I don't know**

Sophia

"I became lifeless."

Sophia is in her mid-thirties, and lives at home with her family, whom she is very close to, and credits with her ongoing recovery. She has experienced depression, anxiety and severe panic attacks for the last decade. She first experienced what she now terms psychosis around four years ago. She described waking up one day and not being able to organise her thoughts and feeling like she was going to die. Sophia believed she and her family were in danger and being watched. She recalls others noticing catatonic like behaviours, which she described as staring without blinking and staying in a fixed position, and extremely labile mood, which was completely out of character for her. There was a prolonged period of insomnia, social withdrawal, self-isolation and self-neglect, leading to extreme weight loss and hospitalisation. Sophia described both herself, family and HCPs not recognising her difficulties as psychosis at the time. She feels she is on the road to recovery and continues to take medication to help stabilise her mood. Sophia was keen to impress the importance of educating people about psychosis, encouraging others to be open about their MH difficulties, and accessing formal intervention. The themes for Sophia are shown in Table 9.

Table 9. Superordinate themes for Sophia

Main Theme
A dramatic and sudden loss of self
Lack of illness recognition by others
A cumulative illness model
A default illness belief of taweez
Family as 'protective but isolating'

- **A dramatic and sudden loss of self**

For Sophia, although she had experienced anxiety and depression since her mid-twenties, her experience of psychosis felt like a sudden and dramatic loss of who she was, leaving a sense that she became lifeless and a passive observer. Sophia describes this as "*the most terrifying experience*" she has lived through. What changed for Sophia was the way she thought; her mind was either an abyss or her thoughts were jumbled and incoherent. She

would spend hours ruminating about what would become of her, and this worry led to catastrophic thinking that she was in danger and going to die. Sophia isolated herself from others and withdrew from family, which she reflects as the start of her experience of psychosis, although she didn't recognise it as such at the time.

> *"It was like um, do you know if somebody's been in a coma, they sort of come out and they learn everything all over again I wasn't in a coma; I was in a different type of coma. It was like I was watching everything but I became blank in the head, you know like in the mind. Everything sort of switched off and it was like a different personality was taken over me"*

This change, from someone who was perceived as timid, very respectful and close to family to someone, seemingly overnight changing character to aggressive, rude and absent led to Sophia feeling like not only had she **lost her identity** but also her sense of autonomy as well. This was reflected in Sophia's experiences of losing pleasure in activities, severe self-neglect and describing catatonic like behaviours and "*zoning out*"

- **Lack of illness recognition by others**

The severity of the self-neglect, including food refusal and consequent weight loss led to hospitalisation. Sophia recalls her experiences were initially interpreted as an eating disorder by HCPs. This delayed recognition by others and had a disruptive effect on Sophia, as she became more passive and unwell, and **detached from what was happening around her**. Perhaps because of this, and because Sophia didn't experience the prototypical characteristics of psychosis, her experiences were not initially recognised or considered in this context. For Sophia there appears to be both visible and invisible experiences. Some elements remained invisible, partly due to Sophia **hiding** some of her unusual experiences, and she recalls not sharing her growing paranoia and cognitive difficulties (rationalising, decision-making), and this seemed to be associated with **shame**.

> ***P: […] They don't want to admit to something because they feel that they feel embarrassed, they feel belittled, and the main reason is because I didn't want to admit I had psychosis but they said but you have got it because the professionals can't make a mistake***

I: why did they think you had psychosis?

P: because I spent a lot of time in my room and I wouldn't come out. And they-I used to think a lot.

Here, although Sophia described some of this in the third person, it seemed like it was something she strongly related to. Sophia demonstrates her awareness of the stigma associated with MH difficulties, but also indicates the **power in the professional voice** to provide a diagnosis, which she seems to have then adopted as an explanation.

- **A cumulative illness model**

Sophia discusses her understanding of her experiences largely in the context of a health illness model. The sense here is that this model has been based on interactions with her healthcare team. Her experiences seem to be understood as both a response to causative illnesses (*"I had anxiety, depression and then psychosis"*) with difficulties preceding one another (*"like a chain"),* and an accumulation of different difficulties, leading to an increased vulnerability. Both seem to be complementary rather than opposing, although she does still struggle with not *really* knowing what it could be.

> *"I was mentally drained with the panic attacks and the anxiety that this opened a door for psychosis to enter"*

Underlying this illness belief, were more general narratives around illness as a reaction to stress and childhood bullying, and illness as occurring to certain types of people, or being triggered by a significant event (trauma).

- **A default illness belief of *taweez***

Sophia initially felt that her experiences were related to "*taweez*", which she described as black magic and witchcraft. This appeared to be a common practice and illness belief held by her family both in the UK and in Pakistan, and seemed largely related to Sophia's behaviour being perceived as out of character by others, acting as confirmatory of possession.

> *"so, um, a few friends of my mother's told her that I think they've done something on your daughter like black magic"*

However, this illness model appears to be a subsidiary framework, and was described in the context of being a last resort and another option alongside health-related illness beliefs and seeking more formal intervention. At the initiation of other family members, Sophia's father sought external validation of the taweez belief model via a spiritual healer. Who disconfirmed this explanation and encouraged Sophia's father to seek formal intervention. Perhaps this also contributed to solidifying the health illness model as a primary explanation for Sophia's experiences.

The conviction in each explanation and the beliefs of the community did seem to impact the type of help-seeking initially accessed, and it was interesting that some of Sophia's extended family members in Pakistan, and the spiritual healer, seemed to hold a **sense of power in influencing the family decision-making**. By proxy there was a sense of **disempowerment** in Sophia's decision-making and passivity in undertaking interventions which seems to stem from cultural considerations, being unwell and the family taking over her care.

- **Family as "protective but isolating"**

It is clear that Sophia perceives the protective family environment as having a positive effect on her psychological wellbeing and recovery. However, this protective behaviour may have also served to act in an isolative way. There appears to be several reasons for this, most salient of which is to avoid the **social stigma** associated with MH difficulties, and the risk of Sophia being given a permanent label, making her different and placing her outside of the community. This seems to indicate a sense of **power the community** can have over a family to silence or even ostracise families where there are MH concerns.

For Sophia this risk of labelling extends across the UK to Pakistan, and she reflects on the impact of poor awareness, and education around MH in both countries. This risk serves to drive the **hiding of MH problems from others**, or framing them under "*depression*", which seemed to be perceived as a more acceptable mental health issue.

There was a general sense that MH difficulties in the community was interpreted under two prevailing frameworks, one of which was illness beliefs related to black magic and the other was an individualistic framework of illness as a result of personal failure or attention seeking behaviour, and poor parenting; both of which risk social rejection. She describes others commonly misattributing her social withdrawal or illness behaviour as deliberate and disrespectful (such as not greeting elders) and the subsequent impact this had on the community's perception of the family.

> *"I'm not trying to seek attention because I forgot to mention. Some of my friends and family thought when I was behaving like this that I was trying to seek attention they didn't understand that I'd a problem"*

Amina

> *"I was scared to even tell anyone about it because I thought they wouldn't understand or anything. I didn't tell my family until a really long time, after a really [nervously laughs] long time."*

Amina is in her early twenties and lives at home with her father and four siblings. She is in a long-term relationship, which she describes as "*up and down*". Despite being surrounded by others, Amina describes an isolated life, feeling distant from her family, being bullied and not having many friends. She feels she has to be very selective in what she shares with her family, and this is related to feeling blamed and unsupported after a severe self-harming incident. She has experienced depression since her early teens and uses self-harm and cannabis to cope with low mood and now the voice hearing. Amina typically hears a single voice, it is male, critical, belittling, derogatory and threatening. Sometimes Amina can hear screaming or several people conversing in the background, although this is much less common. The voice was present throughout the interview, but Amina feels she has gained a better sense of control and likened it to being able to turn the radio down and ignore him to go about her day. She has been able to successfully continue with her retail position and is planning to move out of the family home soon. Amina feels these experiences may have happened for a reason, and she has become a stronger person for them. The themes for Amina are shown in Table 10.

Table 10. Superordinate themes for Amina

Main Theme
Sharing, secrecy and shame
Coping alone
Partial mastery of the voice
Tussling between default and advised illness beliefs

- **Sharing, secrecy and shame**

Amina recalls having a "***terrifying***" experience where she heard an unknown male voice for several nights in a row. Along with the intense fear, Amina was confused, initially locating the voice as external but quickly realising it was inside her head as the voice persisted to day time *("I felt really scared and I didn't know what was gonna happen").* Despite living in the family home at the time, Amina did not share her unusual experiences or that she had accessed support via the GP/EIS for a further nine months. This was due to previous experiences of feeling let down and dismissed, when Amina was encouraged by her sibling to not access formal intervention for fear of what people would think of their parents. This event seems to have had a lasting impact on Amina, and her perceptions of sharing her experiences and help-seeking within the family. There are several times where Amina recalls self-censoring and I noticed it felt like she holds lots back. For Amina, this seemed to be a way to manage the **stigma** of MH, to not be perceived as different/strange and an additional burden to her family. Perhaps most concerningly it was because she doesn't feel like she'll be understood by others.

> *" erm I don't like to, there's stuff that I haven't told anyone not even [EIS staff member], there's a lot of things that I have told, but there is still like a huge part that I know myself affects me but I just can't tell anyone. They just don't, maybe they won't get it. That's what it is."*

Self-censoring, seems to stem from a common practice of **keeping things a secret**. Being open about things, within the family and wider community, seems to be associated with the risk of parental blame and damaging the families honour. This leads to dismissing difficulties, hiding them or framing them as more common, and therefore perhaps more acceptable, MH problems such as anxiety. This seems to leave Amina in a difficult situation,

where hiding things results in having to cope alone, but equally sharing things risks rejection and coping alone. Keeping things within the family and hidden from the wider community also appears to be associated with the perception of the community's beliefs around MH difficulties and more generally around preserving the family's reputation and social standing. In this sense belonging to a close-knit community appears to come with a sense of **community power over the family**. Which ultimately leaves Amina feeling mistrustful of others and like she is alone in her experiences.

> *P: I was thinking that they wouldn't understand much because I haven't seen much mental health within the you know the community, so that's why I thought maybe they wouldn't understand. Coz I just thought you know they were a bit backwards.*
> *I: what do you mean?*
> *P: their backgrounds, are a bit to uhm, coz we're Pakistani's I just thought, they wouldn't be able to understand or they don't have the knowledge about mental health and stuff like that.*
>
> *I: okay, and sorry what did you say about your community and mental health? what did you mean?*
> *P: I feel like no one really talks about it much, it's like, I think it's something like frowned upon. Just like if someone were to talk about it, someone would be like 'ohhhhh'*

- **Coping alone**

There is a profound sense of loneliness in Amina's recollections, in terms of the actual experience of voice hearing, but also in her experiences with family and friends and help-seeking. She recalls losing most if not all of her friends and feeling increasingly **disconnected from her family**. Even though they are now aware of Amina's MH difficulties, and this was initially a source of relief for Amina, her difficulties seem to have been quickly dismissed/silenced and no longer discussed, and it seems like she is back to coping alone.

> *I: does anybody know about the voice hearing?*
> *P: all my family know that, but I don't know if they think it's gotten better or anything but no one asks me about it or maybe they've forgot.*

- **Partial mastery over the voice**

Amina recalled that initially hearing the voice was very anxiety provoking and he would be able to easily distract her. She seemed to enter a cycle of attempting to *fight* the voice and ignore him but being unable to do so and this leaving her feeling very angry and upset with herself, and then reattempting to ignore the voice to manage these emotions. However, over time, it seems her relationship with the voice has changed, and now she feels she can exert partial control over it.

> *"I just got used to it slowly and you know sometimes I can make the voices go away myself, I feel like I can but sometimes I can't. When my mood is low then I just can't. Then when the voices are there, they make me cry."*

- **Tussling between default and advised illness beliefs**

Despite seeking formal intervention within the first two weeks of the onset of the voice hearing, Amina's initial belief regarding it was a spiritual interpretation of possession. This model was perceived as "*crazy*" and "*extreme*" and it seemed she was a little embarrassed to share her illness beliefs related to this perspective.

> **P: erm, at first I thought it was something spiritual. Yeah, I thought it was like you know, I've got the, we call it a Jinn. I thought it was a Jinn or something like that. [nervous laughter]**
>
> I: tell me a bit more about Jinns
>
> **P: erm, invisible devils or something. I don't really hugely know like.**

She recalls her family holding this illness belief, as an explanation for her strong emotional changes (referred to as an 'episode') and her mother initiating contact with a religious man who confirmed possession. Amina described an internal tussle of accepting the possibility of possession and rejecting this as something unbelievable. Both states were associated with confusion and feeling really anxious. This internal conflict led to Amina identifying **evidence for and against this illness belief**, and this was partly by engaging in prayer as intervention, as recommended by others. As this was perceived to be ineffective, it contributed to Amina's scepticism of the explanation. However, it does appear to continue to be a residual

belief, alongside a health framework. A health interpretation was introduced by her EIS team and related to Amina's childhood and trauma experiences. Perhaps, Amina is more familiar with this, due to her prior experiences with formal intervention for depression. Therefore, a health explanation was not perceived as the alternative, and seems to be accepted as an understanding.

> *"Thinking back like now, maybe it was, maybe it was something and I just don't know. But then now with it being related to my mental health. I do think it is because of the past experiences and traumas and stuff like that."*

Group Analysis

During the cross-case analysis, three superordinate, and associated subordinate themes were identified (see Table 11). The following section will discuss each theme, and similarities and differences between participants.

Table 11. Superordinate and subordinate themes for group analysis

Superordinate theme	Subordinate theme	Ismail	Sirah	Asim	Nazreen	Salma	Dalil	Sophia	Amina
Disconnection from self and others	A terrifying and uninvited intrusion	x	x	x	x	x	x	x	x
	Something about me has changed	x	x		x	x		x	x
Doubt and dispute	Points on a journey towards understanding	Searching	Reflecting	In the thick of it	Reflecting	In the thick of it	Searching	Reflecting	Reflecting
	Working with multiple explanations	N/A	Assimilating	Wrestling	Rejecting	Wrestling	N/A	Rejecting	Wrestling
	Testing and proof	x	x	xx	x	xx	x	x	x
	Feeling resigned and overwhelmed	x	x	x	x	x	x		x
	A battle for identity	Fractured	Reclaimed	Conflicted	Reclaimed	Fragile	Conflicted	Reclaimed	Fragile
Power and shame	Feeling empowered			x	x		x		
	Feeling disempowered	x	x	xx	x	xx	xx	x	xx
	Hiding and being hidden	x	x	x	x	x	x	x	x

xx denotes theme as particularly salient for that individual

Disconnection from self and others
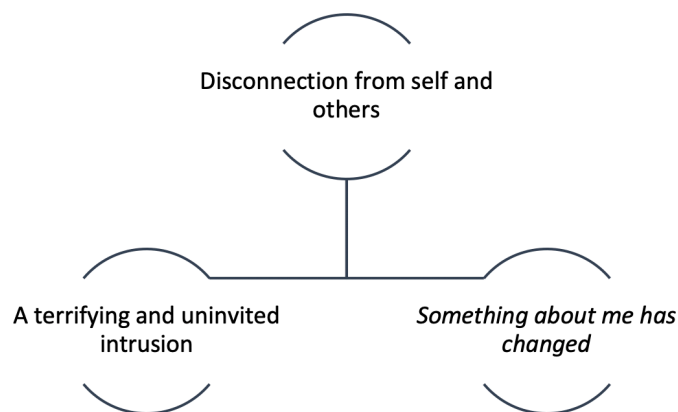
Figure 2. Group analysis: Superordinate theme 1

All participants characterised their experience of psychosis as a sense of disconnection from self and from others. Within this, participants recollected experiences as a terrifying and uninvited intrusion and feeling like *something about me has changed*.

Nazreen recalled a sense of disconnection as her most salient experience, and this driving additional beliefs that she was in danger. Disconnection appeared to also be enforced through the experience of rejection, and in some cases perhaps operated as a protective mechanism to help buffer this.

> *"Yes, I think that the first thing that happened was losing touch with reality. Em that was the biggest thing that happened. I didn't feel like I was here and I also didn't feel like the people around me mattered or … I didn't think that they cared about me or they were doing something like to hurt me?"*
> *(Nazreen)*

Like other participants, Dalil characterised his experience as a difficulty connecting with those around him. This was described as both a precursor and consequence of his experiences.

> *"I think it manifests itself like in life you have to be alone and you can't connect with people." / "it's totally put me out of the family. I'm not that, I'm not allowed to be in the family anymore"*
> *(Dalil)*

A terrifying and uninvited intrusion

Echoing Sophia's recollection of the uninvited intrusion of psychosis being *"the most terrifying experience"* she has been through, other participants described their experiences as "*terrifying*" (Nazreen, Amina) *"frightening"* (Asim), *"scary"* and *"confusing"* (Salma, Nazreen), "*horrible*" and "*not nice*" (Ismail). Dalil recalls one experience with his voice as the "*scariest experience of my life*". And for Sirah:

> *"I didn't know what was going on . . . and umm, I felt just like scared, actually scared as well things like something is going to happen to me."*
> *(Sirah)*

All but two participants described their initial experiences as unexpected and novel. Both Asim and Dalil had heard voices during their early childhood, and therefore the experience itself was not unexpected. For Dalil, his relationship with the voices was ambivalent, but what was unexpected was the how the voices became "*very, very unchallengeable*" over time.

> *"so, I was in a half and half with them, but more to the point, it was more scarier than anything."*
> *(Dalil)*

For Asim, the change in the frequency, tone and content was different, and associated with the voices becoming unmanageable.

> *"Because it was be … harsher, more frequent? Like the second I'd wake up I'd be hearing voices as if people are talking to me? Things like that. Yeah." / "Erm … yeah and it was abnormal because of how much it was negatively affecting me."*
> *(Asim)*

Something about me has changed

The sense of detachment resonated across other accounts and appeared to be associated with a sense that something about them has changed. Ismail for example felt that the onset of his experiences was more insidious, and there seemed to be a period where his reality

seemed to slowly ebb away and thus alter his sense of being and connection to those around him. He associated his experiences with being different and lonely.

> *"you just feel different from everyone else and you just feel secluded, isolated in the way you think; and er, sometimes when you're trying to get your point across people don't understand what you're talking about."*
> *(Ismail)*

Whereas for Sophia, this sense of disconnection was a sudden loss of who she was, and she felt that she became different almost overnight.

> *"just happened over night. They say some things don't happen overnight but this did."*
> *(Sophia)*

Other accounts, reflected becoming or feeling different, changed or a sense of 'otherness':

> *"I just thought I must be crazy."*
> *(Amina)*

> *"and made me someone like who's not really a normal person, if that makes sense"*
> *(Dalil)*

It appears that withdrawing and isolating from family and friends was a common part of experiences. Often this was associated with the overwhelming nature of the experiences, but also as a protective mechanism to avoid social stigma. In this sense disconnection was deliberate for some, for example both Asim and Salma experienced persistent rejection from their family and community, and felt they had no choice but to retreat.

> *"and looking at me like there was something wrong with me and er, I felt outcasted. That's how I felt. I felt like they'd outcasted me. And, and I got paranoid thinking I cannot leave my house. I-I-I can't leave my-cause if I go outside people are going to stare at me and people are going to look at me and they're going to whisper and they're gonna make comments"*
> *(Salma)*

Doubt and dispute
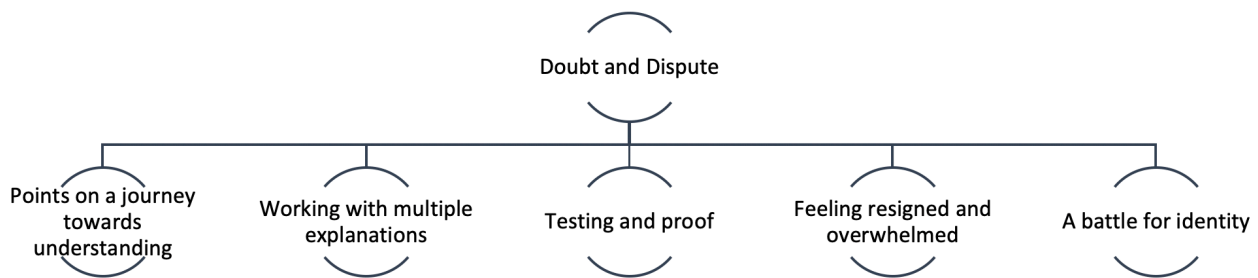
Figure 3. Group analysis: Superordinate theme 2

Doubt and dispute were discussed across cases, regarding the unusual experiences themselves and the stage of understanding the participants appeared to be in; also within the context of working with multiple explanations and testing and identifying proof for beliefs. This theme also resonated through accounts relating to identity and ultimately, there appeared to be pervasive feelings of resignation and being overwhelmed.

Points on a journey towards understanding

Over the course of the interviews it appeared as though participants were at different stages of their journey towards understanding their experiences. There appeared to be a temporal quality to this, in that a more stable understanding was associated with the passage of time, and some distance from the unusual experiences. Both Ismail and Dalil seemed to be in the process of searching for an understanding. Both were in some ways still experiencing more extraordinary ideas and beliefs, and/or perceptual anomalies, and it appeared that this prevented them perhaps from stepping outside of the experiences to reflect on them during the interview.

> ***P: they don't mean anything to me***
>
> *I: mm*
>
> ***P: I wished this never happened***
>
> *I: yeah*
>
> ***P: I don't know where it come from, I don't know where it crept from***
>
> (*Ismail*)

"I dunno. It's just, there's something unexplainable, to be honest"

(Dalil)

In contrast, both Asim and Salma where *in the thick* of exploring and developing an understanding. Although both were also experiencing perceptual anomalies at the time of the interview, they had begun to reflect on their experiences and what they may mean. Although Asim notes here he has looked back on his experiences, it seemed overall, he was still in the process of deconstructing them to identify meaning:

> *"Like I said I looked back at everything. Tried to figure out what was real. What wasn't? Yeah. And the main thing I took from it was understanding my … family. My culture. My religion. And … categorising each thing. Splitting it."*
> *(Asim)*

Sirah, Nazreen, Sophia and Amina, appeared to be reflecting back on their experiences, and how they made sense of them then, and how they have come to make sense of them over time.

> *"I feel like they all linked like the psychosis came along with a lot of depression, anxiety. I think it started off with depression because em … I did actually go onto some tablets, Fluoxetine, I think it was called? And em I think it all stemmed from depression and anxiety. Em I've always been quite an anxious person. And I think the psychosis actually came from that, because my an, my anxiety fears built up. It just built up so much that I just couldn't handle it anymore and I think that's what happened. I just lost control. And that's what I mean when I said I lost touch with reality."*
> *(Nazreen)*

Working with multiple explanations

For all participants there appeared to be a default explanation for experiences, relating to spiritual/religious understanding. A health framework was also discussed, often in the context of its provision from HCPs. There appeared to be an element of feeling

disempowered when it came to adopting the EIS explanation, in that there was a sense that participants *had to* accept the dominant discourse shared/enforced on them by HCPs.

Where there were multiple explanations, participants appeared to be at different stages in establishing a system of understanding. Explanations appeared to be dynamic, and there was a fluidity in sense-making. There appeared to be three sources of sense-making: the self, family and community, and formal services. For each individual, the influence of each source varied, although all demonstrated a temporal quality and recursive process in developing an understanding. Although there was some level of a shared understanding between the self and other sources, there was little overlap between family/community sense-making and formal services sense-making. Figure 4. illustrates where individuals appeared in this construct: assimilating (Sirah), wrestling (Salma, Amina and Asim), or rejecting (Nazreen and Sophia) explanations.
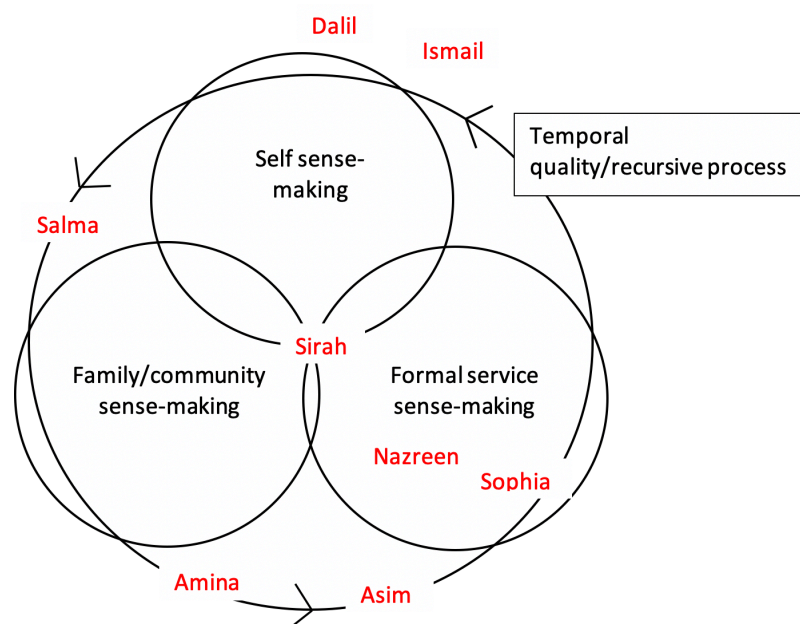
Figure 4. An illustration of the process of sense-making for participants.

Although both Ismail and Dalil recounted multiple explanations, both appeared to still be contemplating the experiences themselves (e.g. the intent of the voices, unusual beliefs) and the meaning of them was thus still elusive (see Figure 5).

> I: yeah. And why do you think that might be happening
>
> **P: lack of education of how to deal with people**
>
> I: okay

P: now if I get psychosis it's like you're loving something else and the way things are meant to be you love that, and then it gets stuck in your mind and you can't get rid of it.

(Ismail)

"it's just I feel I'm just sort of spiralling out of control in some way. Like they're trying to take over my life and I don't know who to turn to or what to turn to. I don't know who can make this problem go away, of hearing voices"
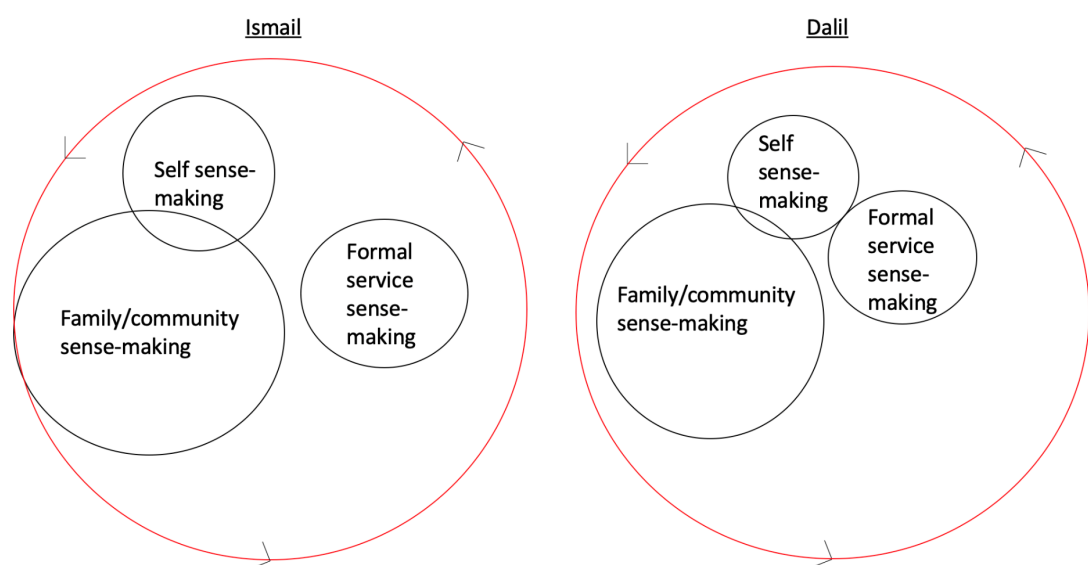
(Dalil)

Figure 5. An illustration of Ismail and Dalil's sense-making.

Ismail's beliefs overlap with his family's and community sense-making (e.g. will of/punishment from God) and he rejects the diagnostic explanation from EIS. Dalil too rejects the EIS explanation of drug use, and struggles to make sense of his experiences, but feels they could be related black magic, as confirmed by his Imam.

It appeared that for Asim, Salma and Amina the multiple explanations created conflict and competition between them. There seemed an unhelpful tension of two seemingly opposing explanations, and distress and confusion stemming from the attempt to reconcile them.

"so, it's like when, when I wasn't in a situation that was religious, if I wasn't praying, and the stuff that was happening, what I was getting told from here [gesturing around to EIS team building], that was making sense […] but when I was doing

something in regards to reciting something or praying, that made sense. So, I was like stuck in between. So, it was like, like when I'm doing this, this makes sense. When I'm doing this, this makes sense because when I'm doing this then that doesn't make sense [gesturing using both hands as a scale]"

(Salma)
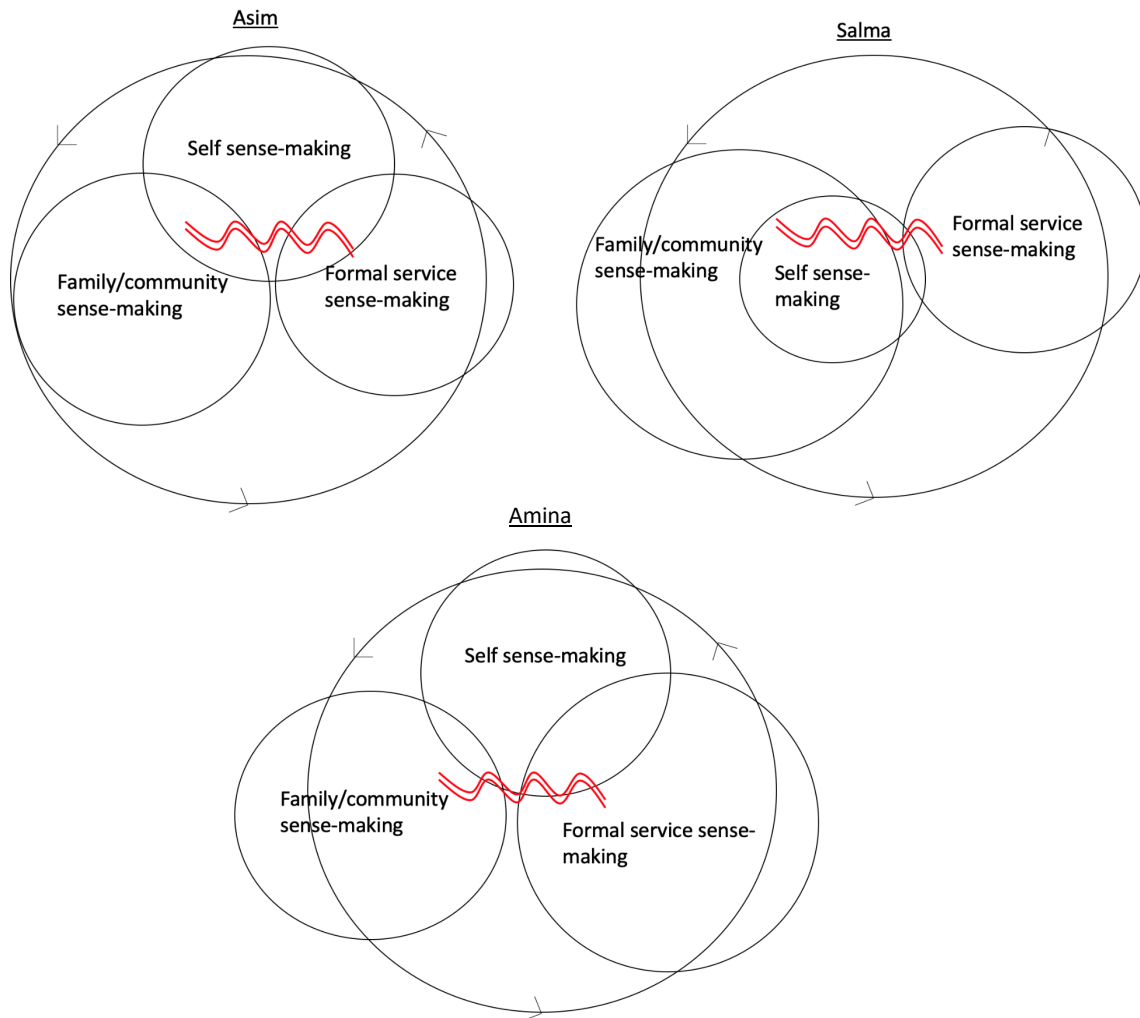
Asim

Salma

Amina

Figure 6. An illustration of Asim, Salma and Amina's sense-making.

All three individuals appear to be wrestling between explanations (denoted by red lines in Figure 6). This seemed most acute for Salma and Asim, who both spoke at length about their struggle to juggle between spiritual and health interpretations.

Both Nazreen and Sophia also initially held spiritual explanations for their experiences and recalled the confusion of holding multiple explanations (see Figure 7). However, for them, it seemed ultimately one explanation was rejected over the other. In both cases the spiritual explanatory model was rejected. It appears for Nazreen this was a way to manage the sense

of confusion and avoid some of the shame and negative connotations associated with "*nazar*".
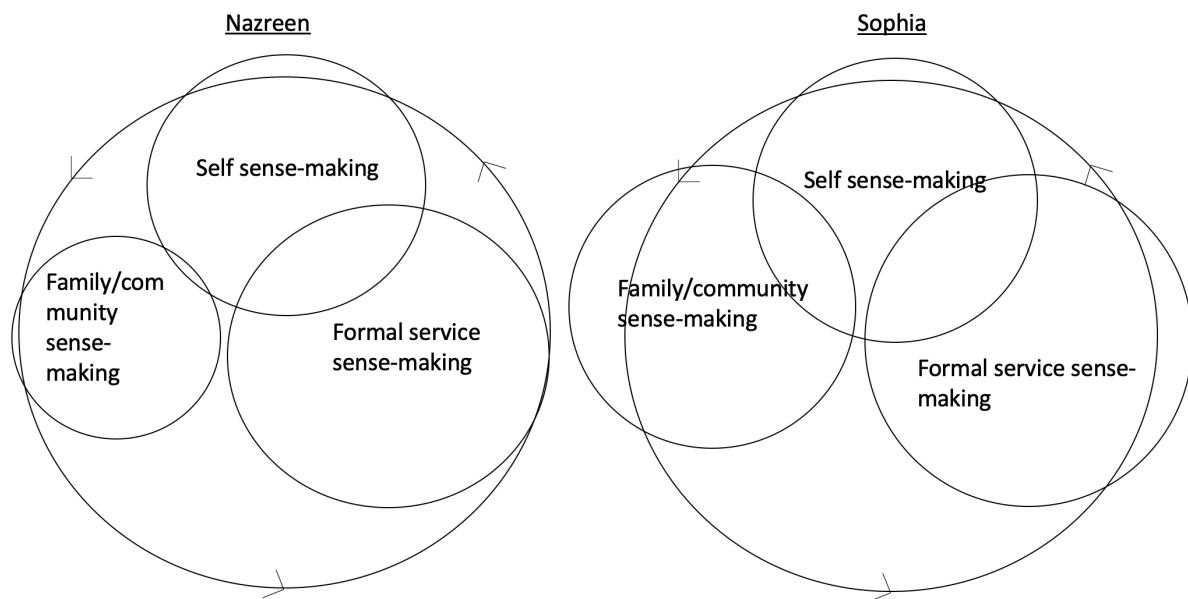
Figure 7. An illustration of Nazreen and Sophia's sense-making.

Although Sophia initially understood her experiences in relation to "*taweez*", this explanation appeared to be perceived as *another* interpretation, to cover all grounds, so to speak, and was ultimately rejected after being disconfirmed by a spiritual healer. Although she impressed she still held strong beliefs about spiritual/religious interpretations of illness.

> *"he contacted a spiritual healer because what happened is um, er, obviously he was*
> *gonna seek the help of the professionals first. That was just an option because, it's*
> *just a option because they sorted of suggested it, you know home, back home in*
> *Pakistan they said, 'Well try everything. Even contact a spiritual healer if you have to,*
> *to get some answers' because um, they thought probably there's some dark entity,*
> *witchcraft or black magic that's on her. She's probably drank something from*
> *Pakistan that's affected her head"*
> *(Sophia)*

Sirah, appeared to be the only participant who felt both explanations could be accommodated and assimilated the models into a system of beliefs (see Figure 8). She reflected that some of her experiences are likely due to "*nazar*" such as low mood,

depression and feeling out of sorts, as interpreted by her family and community. However, feeling watched was explained by the EIS explanation of paranoia and psychosis.

> *"I thought like, I thought it might be evil eye and I was thought I was stressed at the same time. So, both things stress and evil eye. That's what I thought it was and it was that kind of, yeah, I think that's what triggered my psychosis as well just thinking that work, work, work."*
> *(Sirah)*

Sirah

Self sense-making

Family/community sense-making

Formal service sense-making
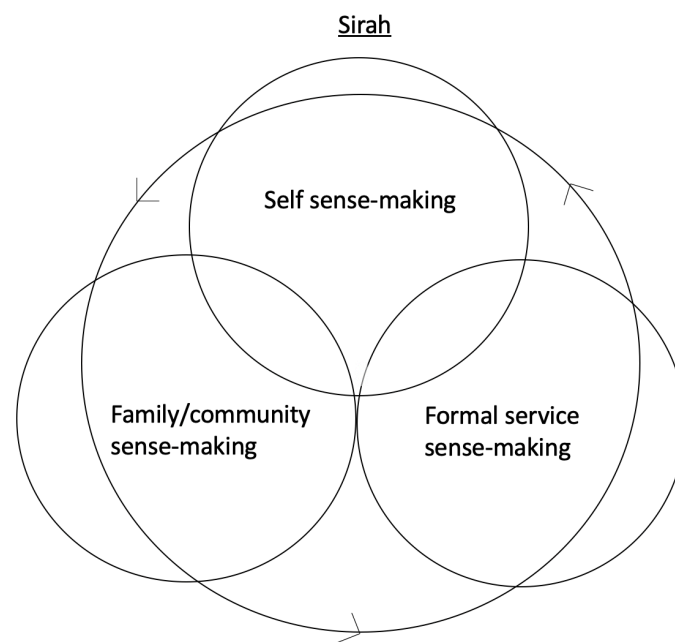
Figure 8. An illustration of Sirah's sense-making.

Testing and proof

As part of the recursive process of working with multiple models, all participants spoke of testing and identifying proof for explanations. For health interpretations, this appeared to largely consist of internet searches. However, this process seemed more complex and intricate for spiritual explanations. All participants sought external validation from family and community, including Imams or religious scholars/leaders/healers. Some participants spoke of performing rituals (Sirah, Salma, Nazreen) that could identify "*nazar*". Asim recalled sharing his experiences with his best friend, which helped confirm that he had experienced Jinns as well as speaking to Imams and his uncle, who is a religious scholar.

"And I've told him about the experience with Jinns. Sometimes he was there! When I, like when the Jinns were there and he'd like feel it as well. So that's how I knew it wasn't always erm … psychosis or something else. I knew part of it was real. Part of it, yeah, is real."

(Asim)

P: Em and em … yeah but it wasn't that cos we did get it checked.

I: What do you mean?

P: You can go to someone to get it checked like a religious scholar.

I: Okay.

P: But that's ruled out cos obviously it wasn't that.

(Nazreen)

I: did you have much contact with the general community

P: I did, yeah. I had contact with the local Imam and stuff like that and I told them, but they said it was black magic

(*Dalil*)

At the initiation of other family members, Sophia's father sought external validation via a spiritual healer. This illness belief was subsequently disconfirmed by the healer, who encouraged Sophia's father to seek formal intervention. Salma spoke at length about her scepticism of both explanations, but particularly the spiritual explanation of black magic/possession leading to this recursive process of seeking external validation from her sister-in-law, several religious leaders and using prayer and/or rituals for evidence and intervention.

P: from what I did with er, the possession thing

I: yeah

P: that seemed more to me

I: what do you mean?

P: because it's like the more I dug into it the more it justified it. So, like the more little things that I did cause when I did the recitation thing

I: mm

> **P: I did it again. Cause I, I was like maybe it's a one-off thing. So, I did it again and like the same thing happened, and then I basically tried to pray again; and er, every time he knocked me away from the prayer mat, I went back, and I stepped back on it.**
>
> *(Salma)*

Both Salma and Amina recalled the validity of the religious leader's explanations being associated with community reputation and exchange of money for services. Both also spoke of the in/efficacy of medication impacting the level of conviction held in an explanation.

> **P: so, from where I was concerned, it was like the medicine, what it's supposed to do, it's not doing it. Cause I got put on Aripiprazole that was supposed to stop the voices but even though I was taking it, it wasn't, it was still there**
>
> *I: why do you think that was?*
>
> **P: because the more I was umm, looking at it from the religious perspective, I was like if it's that then, that's why the medicine's not working.**
>
> *(Salma)*

Feeling resigned and overwhelmed

In some way, every participant's experience was characterised by feeling overwhelmed and resigned. This was in the context of the actual experience (e.g. voice hearing, visual perceptual anomalies, having unusual ideas and beliefs), the experience of help-seeking and working with multiple explanations. Ismail was overwhelmed by the slippery nature of reality and resigned to not knowing what the *truth* is and whose reality to trust, his own or that of the HCPs. Asim described feeling overwhelmed by the frequency and harsh tones of the voices, and the struggle to find an explanation for them and identify which experiences were *real* and which were part of the psychosis. There was a sense of resignation in having to keep parts of his identity hidden, and not being able to share his feelings and experiences with those around him. Similarly, Amina seemed overwhelmed by the intrusive nature of the voice hearing and resigned to its continued presence, and feeling she has to cope with her difficulties alone.

"I just got used to it slowly and you know sometimes I can make the voices go away myself, I feel like I can but sometimes I can't. When my mood is low then I just can't. Then when the voices are there, they make me cry."

(Amina)

Salma, Sophia and Nazreen's accounts were also characterised by confusion and feeling overwhelmed. For Nazreen this seemed particularly salient in her efforts to get people to understand what she was experiencing at the time.

A battle for identity

Sirah, Nazreen and Sophia characterised their experiences as briefly losing their identity and having an 'illness identity'. They associated a reclamation of identity with recovery. This repossession was associated with re-establishing roles in their family, participating in occupational activities, socialising and employment, and a positive change to someone who is stronger, more knowledgeable about themselves, and their MH, and more mature and independent. For Nazreen, her reclaimed identity was associated with acceptance of MH difficulties.

"But now I know what I would say. I would say … yeah maybe I do have a mental health condition. Back then I didn't want to believe it! That even if I did … cos it's a big thing, em to, to make yourself believe that you've got a mental health condition. And obviously now it's just something that's with me now. I've accepted it. And em … it's not a big deal honestly like people have worse, people have worse situations in the world. So as long as I'm on medication and I'm stable and stuff. That, I just appreciate that, what I went through is gone and I hope it doesn't come back. So yeah."

(Nazreen)

For Ismail it appeared as though his identity has become fractured, divided between pre- and post-experiences. The current identity is associated with deficit and loss, and no longer having the same potential or being the same person.

"it wasn't like this before. I had my brain; I had my intelligence, so I had like mental cognition. I mean it was really good. Er, my brain was really like responsive but like it's now it feel like the heart of the mind there's nothing there anymore. It just feels like it's just a canvas that's just painted grey"
(Ismail)

In Salma and Amina's experiences there was sense of identity as fragile. Salma had built a new identity, after her trauma experiences, but her unusual experiences seem to have brought to stark light the fragility of this identity, and Salma seemed to be grappling with holding on to *an* identity, although she was unsure who she truly was.

"So, basically, I was in autopilot mode so I wasn't really discussing, like I wasn't sitting with anyone and saying I need to tell them how I feel so I can, I just pushed it and just left it. And, because I got so good at faking it until you're making it, kind of thing, like I couldn't tell if I'd actually made it to the other side or I got so, I'd perfected it so well that um, I could just get up and someone new would come. I'd just sit and talk, all confident. And, I never thought about it."
(Salma)

Although perhaps not as explicit, I felt that Amina's sense of identity seemed fragile also. There was a sense that there was vulnerability and loneliness associated with who she is and her experiences. Both Asim and Dalil spoke of a sense of conflict in relation to their identity. Both reflected on being bicultural individuals, and struggling to find belonging across two different cultures. Asim spoke about the conflict in identity arising from his heritage culture and residing in a host culture. He describes feeling that being a part of but not *really* belonging to two dissimilar cultures has created a sense of detachment from both identities and conflict between them. This was reflected in his interactions with family and the MH system, in that with both he does not share the other identity, and associated values and beliefs. Asim described how family and community cultural norms regarding honour, respect and expectations served to increase his sense of detachment from his community and create a split between who he is and who he is expected to be.

Although Dalil belongs to a different SA community, he too seemed to feel a sense of disconnection in relation to identity. Dalil's sense of identity was discussed in the context of social rejection and the influence of the community's ideas around identity. Dalil discusses the difficulties and the frustration of belonging to the Bangladeshi community and his desire for acculturation, and the impact of this on his self-acceptance. There seems to be a sense of conflict in identity, of being Bangladeshi but being perceived as a *'coconut' ("someone that's a White man wanna-be"),* and the negative connotations associated with accessing formal support services within the community; thus perceived as being different, acting outside of community norms and exposing the family to dishonour.

> *"I find, I find that very offensive, because at the end of the day we live in England and it's dominated by English people so, we should want to be like English people and strive to be like them and be the same as how they are and the way they live and eat. And that should be our way of life because we're in their country end of day" (Dalil)*

Power and shame
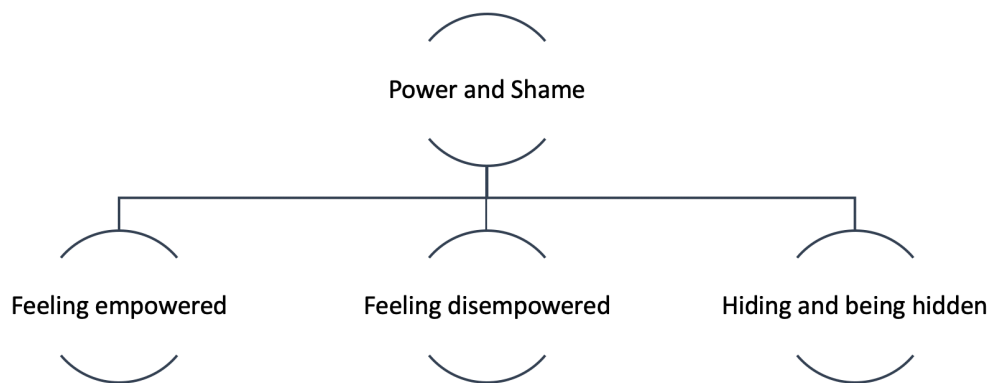
Figure 9. Group analysis: Superordinate theme 3

Power and shame resonated in all participant accounts; for some, perceptual anomalies led to feeling empowered, for others their experiences were largely associated with a sense of disempowerment and shame; and all participants characterised their experiences in the context of hiding or being hidden.

Feeling empowered

Both Asim and Dalil had experienced voice hearing since early childhood. For Asim, it was a form of companionship, and associated with his idiosyncrasies. Like others (Salma, Sophia) faith was a protective factor for Asim, and parts of his identity appeared to provide a sense of empowerment.

> " I think it's been helpful for me to be a Muslim. 100%. Erm I think society looks down on you. Some … having … for being Muslim where it comes to … many things. Not just mental health. So it wasn't, it's not…. society makes it harder, but when you're praying it's easier."
> (Asim)

Dalil too heard voices as a child. It seemed these were a response to traumas, and with each trauma experience the voices became more prominent, and a source of company, comfort and protection. It appeared that they provided Dalil with a sense of power, and he was initially able to control engagement with them. Over time, although this relationship has changed, the voices can still be benevolent, protecting Dalil from harm and warning him of danger. Dalil's sense of empowerment is also tangled with his more extraordinary ideas and beliefs, and he finds it difficult to delineate where they come from because of this.

> "it was different; it was very enlightening in some way because in some ways it was like doing something good for me by telling me things. And other ways it was kind of scary because I didn't know where the voices were coming from or whose they were"
> (Dalil)

Nazreen's initial experiences were also appraised as positive and associated with a sense of empowerment.

> **P: Well first of all hearing the voices. I didn't know where it was coming from and … I actually thought it was normal because I thought in my head someone was like talking to me. [...]I don't know I thought I was like some spiritual thing! I don't know … em that I knew I could talk, I had like a special power to talk to people. That's how I felt at the time. Like in my head! Yeah I don't know. I just thought I**

was some spiritual thing! So. But that wasn't it. It was just a hallucination. At the

time I didn't know what hallucinations were! I just thought oh I'm a genius. I can

talk to people in my head or whatever! But … yeah. Basically.

I: How did it feel? To be able to do that?

P: Well I thought I had some sort of power at the time. So it made me feel good

but obviously I wasn't feeling good. I was going through psychosis. It was bad, but

that did make me feel good! That I thought I had a power, but I didn't.

(Nazreen)

In all three individuals, it appears that the sense of empowerment was challenged most acutely when those around them did not share this or labelled this as part of an illness. Asim for example, had a positive experience of sharing some of his experiences with Jinns with his best friend, and this allowed for a continued sense of empowerment. Whereas for Dalil and Nazreen, some, if not most experiences have been challenged by HCPs and framed as part of psychosis. This challenge may perhaps lead to a sense of disillusionment for service users, when their positive appraisals of experiences are quashed.

Feeling disempowered

A sense of disempowerment resonated strongly across individual accounts not only as part of the unusual experiences themselves but also in the context of belonging to the wider SA community and help-seeking (both formal and informal). For some, feeling disempowered was a salient part of their unusual experiences (Asim, Salma and Dalil). Although Dalil also spoke of feeling disempowered through his interactions with others, his disempowerment was largely characterised by the sense that his voices held power and were omnipresent.

P: like I couldn't escape from it if I went to another country they'd be there. If I

went to the next city they'd be there. If I was in any environment they'd just turn

up. And they tried to tell me that I was paedophile but I'm not paedophile

I: who tried to tell you that?

P: the voices

I: ah, right, okay. And how was that experience for you?

P: that was the scariest experience of my life cause it happened in jail, and

obviously in jail it's a rough environment

(Dalil)

For all disempowerment was reflected in their interactions EIS or other institutions. For example, where power had been signed to the professional voice, this appeared to be at the expense of their own. A power imbalance between participants and EIS seemed to have heavily influenced their understanding of their experiences. This appeared to create a sense of conflict for the participants internally and with others. For example, it seemed like Ismail had lost a sense of power, and other people were taking charge and he felt pushed to go along with their ideas and beliefs. Asim, Dalil, Salma and Amina too described similar experiences of feeling disempowered to voice their explanatory model. Although Nazreen's experiences were perhaps not as explicit, disempowerment was demonstrated in her interactions with others and the sense of shame that was associated with holding a spiritual explanatory model. Disempowerment was reflected in accounts of compliance with medication, interaction with the police, and the imposing of power when others constructed 'reality' for participants.

"I felt comfortable talking to them but there was always a backlash; there was

always something where they wanted to pin me down . . . after . . . yeah, pin me in a

way like because I've got unconventional way of looking at it at that time th-e-y, they

really wanted, they didn't like it so"

(Ismail)

Ismail noted that through his continued interactions with EIS staff he was able to identify ways in which he could reclaim a sense of power, via feeling respected by staff, not feeling judged for his ideas and beliefs and being listened to and not dismissed as someone who has psychosis.

"to understand first of all where a client is coming from; just cause he's got psychosis

and everything doesn't mean he's going to have psychosis tomorrow"

(Ismail)

Lastly disempowerment resonated through accounts of interactions with family and community. Asim, Dalil and Ismail reflected on disempowerment via feeling belittled and dismissed. Other accounts also characterised powerlessness by belonging to a close-knit community, restrictive family environments, pressure to adhere to cultural norms and isolation and loneliness. Like others, Amina's account reflected a sense of power held in her community over the family's reputation, the consequence of which is being in a position of disempowerment regarding help-seeking.

> *"I had self-harmed really bad like, and it wouldn't stop and I thought I was gonna die so I rang my sister and I was like can you please take me to the hospital and she was like 'no you can't go. What's mum gonna say, what's dad gonna say'. So that's why I never, after that I never did tell anyone about how I felt or even if I self-harmed I just kept it to myself."*
> *(Amina)*

For Salma, power and disempowerment appeared to be a ubiquitous part of her life, experiencing control from her ex-husband, family and the voices. These experiences have left Salma struggling to identify her sense of power. Her account is peppered with experiences of disempowerment, when help-seeking for domestic violence and psychosis, being ostracized from her family and community and to feeling that HCPs held the power to explain her experiences and intervene.

> *"So, and plus, it would've been like if my father, with him being the head of the family. If he said I believe you, everybody would've rushed"*
> *(Salma)*

> **Now when the ladies came over, cause they came to my house**
> *I: mm*
> **P: and it was two White ladies, and er, when they turned up, he was already there. Cause er when I came to during the day shift again it was a White lady at the hospital, and she turned round and said that I was very lucky that I have a very loving husband.**
> *[…]*

P: and when they were leaving I were literally grabbing on to the lady's arm for dear life. And she did not, she was like, 'You're a very lucky woman. You have a very loving husband.'

I: mm

P: and then after that happened, he locked me in a storeroom for nine years

I: oh my gosh

And that happened for nine years until I was like, you know what no one's gonna do it. Just me. And I was like . . . get out of my life!

(Salma)

Hiding and being hidden

Closely linked to this sense of disempowerment was secrecy and hiding things from others (including in interactions with EIS), or being hidden from others, such as extended family and the wider community. As with the previous theme, all participants spoke about keeping things a secret, holding things back and self-censoring. If MH difficulties were shared, they were often reframed as stress or more common difficulties such as anxiety and depression. Prominent in this theme was the need to avoid risk of shame and social stigma associated not only with MH difficulties, but also more broadly (being in a relationship, drugs and alcohol).

> *"and even though they see all the signs, it's like they turn a blind eye to it. It's one of those things, and if you push it under the carpet it's gone, kind of thing. And that's how it's always been. So, but with my family it's always been the case with that, with anything. So, it's not just mental health issues or um, anything like that."*
> *(Salma)*

> *"Our reputation. 'What are people gonna say?'"*
> *(Amina)*

> *"Yeah. So you can't, you can't mention, for example you can't talk about weed! And you can't. So when you're talking about your issues you can't tell them everything. You can't say I'm using weed to … fight everything that's going on. I'm using it as a coping mechanism. You can't tell your father, you can't tell your parents that! Erm*

because … well … it's frowned upon in your culture. It's frowned upon in your religion. It's both in that situation." / "No! Like I said about culture. You don't talk about mental health."

(Asim)

Summary

For these individuals psychosis was characterised as a sense of disconnection from self and others. This was in the context of a terrifying and uninvited, and for most novel experience, that made people feel that something about them is different. There appeared a sense of doubt and dispute in their journeys towards understanding, working with multiple explanations and identity. For all, this led to a process of testing and identifying proof, and for most it felt like psychosis was overwhelming and associated with feeling resigned. Whist some individuals noted a sense of empowerment via their unusual experiences, this did not seem to last. All noted disempowerment via the experiences themselves, their interactions with family and the wider community and via formal services. Disempowerment was also reflected in the shame and stigma associated with MH difficulties and the seemingly common practice of hiding things from others, or being kept hidden.

Chapter 5

- Discussion -

Interpretative phenomenological analysis was used to address the broad research aim of exploring how British SA individuals experience and conceptualise psychosis. This chapter will provide a summary of the findings and how this work sits within the wider literature concerning this topic.

Summary of findings

Several themes were identified in the individual analysis. Some of these resonated across accounts and three themes were identified in the group analysis: 1. Disconnection from self and others, 2. Doubt and dispute and 3. Power and shame.

Theme 1. Disconnection from self and others

For the participants of this study, psychosis was characterised as a '*terrifying and uninvited intrusion*' in their life, leading to a sense of '*disconnection from self and others*'. Whilst there were differences in the nature of the intrusion between individuals e.g. hearing voices, being watched and/or feeling in danger, or having extraordinary ideas and beliefs – the experience of being under threat and fearing for themselves and others, seemed to be shared. The unfamiliarity of the experience, difficulty recognising signs (by self and others), denying there was a problem or anticipating that problems would recede naturally seemed to impede help-seeking and illustrated that some individuals needed to develop a sense of 'illness' before seeking help or accessing support. For example, participants described having experiences for some time before an untenable social situation led to help-seeking (often initiated by others) or interpreting their experiences as signs of a physical illness.

Furthermore, participants described others (e.g. family) interpreting behaviour outside culturally acceptable limits as signs of being 'unwell', such as not being a hospitable host, talking back to elders and risk taking (see 'Unfamiliar experiences', 'Down-playing, self-censoring and stigma', 'Frustration of feeling silenced', 'Pervasive rejection', 'A dramatic and sudden loss of self', 'Lack of illness recognition by others' and 'Family as protective but

isolating' subthemes). For example, Sirah noted that being confrontational with others was interpreted as out of character for her by her parents and therefore an indication that she was unwell. Similarly, Sophia described how ignoring house guests was perceived to be out of the ordinary and therefore a sign of having an illness. Nordgaard et al. (2021) propose there is a paradox in having a novel experience and also being expected to have the ability to identify it as a MH difficulty that requires intervention. This is perhaps especially significant for this sample: participants described being unaware of psychosis and services and the language surrounding it, and recalled that this was common across their community (see individual subthemes for Salma, Nazreen, Sirah and Sophia). This is reflected in other reports exploring SA experiences of accessing MH support (Prajapati & Liebling, 2021).

Overall, the absence of the term psychosis, associated language (e.g. paranoia) and the social construction of illness suggests there are cultural differences in the meaning and values assigned to what may have traditionally been referred to as symptoms under a Eurocentric model. In light of this, cultural sensitivity would involve being aware that psychosis is constructed, communicated and understood differently in the SA community and that contact with formal services may include the external imposition of meaning.

Detachment from reality was a salient experience resonating across several accounts. Previous research exploring the experience of psychosis in SA women has also noted a sense of invasion and suspicion (Corin et al., 2005). The findings from this study extends these results, and shows that the sense of intrusion felt as part of the experience of psychosis is across genders and can lead to a detrimental impact on engagement with others, including formal services. Where detachment from reality and disconnection from others is experienced, this may make individuals more cautious about engagement with an unfamiliar and perhaps intense service model. An example of this is Dalil's description of his clashing relationship with his EIS team, where he was worried about the team imposing their reality on his own and the sense that he has to comply with their demands, leading to being wary of engagement with them.

Dalil's and Ismail's experiences could be characterised as "poor insight". However, another way to interpret this is using Bleuler's (1950) phenomenon of "double-booking", whereby people experiencing psychosis have the ability or dilemma of being able to exist in two

realities: a solipsistic one and one that is shared with their social world (Henriksen & Parnas, 2014). Where realities conflict, and service users appear to struggle to co-exist in them, rather than labelling someone as 'having poor insight', it may be more prudent to work with each individual to explore the development of an idiosyncratic personal combination of realities. Avoiding imposing realities may build trust, empower the service user and reduce disengagement or self-censoring.

Henriksen and Parnas (2014) suggest that the idea of poor insight has become synonymous with the concept of psychosis. Services should consider the disconnections between views of service users and staff are, at least to some extent, a way for people to cope with a profound and rigid shift in their sense of reality and a difficulty to think meta-cognitively about their ideas and beliefs. For example, for Ismail and Dalil it appeared their more extraordinary ideas and beliefs were still being experienced, increasing their sense of disconnection from others. They appeared to struggle more than the other participants to critically reflect on the validity of their ideas/beliefs post-hoc (see 'Points on a journey towards understanding' subtheme).

However, it may not be enough for services to address metacognition to increase 'insight'; more appreciation should be given to the impact of the lived experience of psychosis being characterised by a fundamental change in one's core sense of identity (see 'Something about me has changed' and 'A battle for identity' subthemes). Chernomas et al. (2017) note that beliefs which are considered delusions by services have important meanings for people. Professionals could explore the meaning behind more extraordinary ideas and beliefs, given that the interpretation of some accounts given by participants in this study appeared to indicate reasons behind them, some of which seemed to be specific to cultural expectations and values. This may help maintain engagement and mitigate the risk of the individual feeling rejected and disempowered.

Disconnection from self and others was also reflected in participants' experiences that '*something about me has changed*' and worries and fears that they had become "*abnormal*", "*different*", "crazy", "*mental*". This subtheme echoes the work of Sass and Parnas (2003), in their phenomenological Ipseity-disturbance model of schizophrenia, which proposes that it is the fundamental change in the "me-ness" that characterises the principal

disturbances involved with this phenomenon. Change in self was also described in the context of others (e.g. friends, family and community) reporting that individuals were "*not themselves*", "*being out of character*", "*weird*" and "*frightening*".

Some themes identified in this study resonate with those reported in McCarthy-Jones et al. (2013) and Hansen et al's (2018) systematic reviews of studies conducted in majority White samples. Furthermore, in line with other IPA investigations into the experience of psychosis which reported themes related to the role of the voice and relationships with voice (Rácz et al., 2017) and emotional responses to extraordinary ideas and beliefs, such as fear, uncertainty and loss of control, loss of identity and adjustment (Todd et al., 2009) participants in this study also identified similar experiences. Overall, this suggests there are phenomenological overlaps in the experiences of psychosis between ethnic groups.

However, this study's findings also diverge from these reports and Eurocentric conceptualisations on several counts, including, but not limited to culture specific content of the experiences (e.g. Salma seeing a churel, Asim and others hearing, sensing or seeing Jinns); the degree of family involvement; paternalistic influences; the power of the community; the impact of bicultural identity, racism, discrimination and social exclusion (from indigenous and host cultures). This suggests that although there are commonalities in the experience of FEP, the complexity of the cultural context is a strong influence. Distinctive cultural influence was perhaps most strongly evident in how people conceptualised their experiences, how they managed their sense-making and where they sought support for it.

Convergence and divergence of the experience of FEP across ethnicities suggests that although psychosis is an idiosyncratic experience, some experiential themes are shared between and within ethnic groups. This study proposes that themes can be extrapolated and applied to other groups and be used as a framework for how services can work with people who experience FEP and hold multiple, sometimes conflicting conceptualisations. Importantly, the findings from this study strongly suggest that whilst themes could be more widely relevant in the experience of FEP, services appreciate the impact and importance of cultural nuances when working with individuals with marginalised and intersectional identities. This work demonstrates that there are cultural differences in the experience and

conceptualisation of FEP, but much more research is needed to increase theoretical transferability.

This study identified a culture-specific interpersonal dimension to disconnection. Participants recalled the inherent risk of becoming 'part of the rumour mill' and familial shame when experiencing FEP (and other MH difficulties) and belonging to a close-knit SA community. This resonates with other accounts in SA populations (Time to Change, 2010), but does not appear to be a strong finding in research conducted in majority populations.

In this study, disconnection appeared to be both an unintentional consequence of the experience, and also a deliberate attempt to help manage shame and social stigma associated with MH difficulties and mitigate the risk of *permanent* stigmatising labels (also see '*Hiding and being hidden*' subtheme) – reported to have a significant impact on social standing and community relationships. Perhaps because of this, participants often described down-playing and self-censoring in their interactions with others, both when the experiences were most acute and after, when interacting with formal services (and for some it was felt during the interview). One explanation here is SA individuals may have a more socio-centric self-concept, which privileges relationality, which may find itself at odds with an egocentric self-concept privileged in the current Eurocentric healthcare system (Langa & Gone, 2020).

Societal stigma has been consistently associated with BAME groups where there is more than one episode of psychosis (Loganathan & Murthy, 2011; Islam et al., 2015) and identified in IPA investigations exploring psychosis (Knight et al., 2003). However, this study demonstrates that the impact of stigma on one's social capital in the SA community can be rapid and immediate, even for those experiencing FEP and entering services for the first time. In light of this, services need to consider how to support SA service users, without exacerbating loss of social network and mirroring distressing experiences of intrusiveness. They also need to consider that due to experiences and engagement with formal services, SA service users may have lost sources of support they could have otherwise accessed. Therefore, professionals will need to carefully consider the wider cultural context within which the service user exists, and the impact that this has on working with them and the sharing and disclosing of experiences.

In this study participants described self and/or community perceptions of individual accountability in pathways to care, such as smoking cannabis, attracting negative attention or karma. Services may need to consider wider discourses around MH difficulties within the SA community, and how this positions individuals to not seek help from others or be stigmatised if they do. For example, participants described that their position in the family meant 'having to hold it together', or avoid bringing shame and disrespect on the family or focusing on taking care of elders or younger siblings as priorities. Services need to be as aware as possible of the sociocultural barriers to help-seeking and engagement that exist in the SA community, in order to provide meaningful and appropriate support. The EIS model of healthcare is progressive, however, this study suggests that there are cultural differences in experiences that are impacting communication and interaction with services and acting as barriers to optimal service utilisation.

Theme 2. Doubt and dispute

Of the studies conducted in South Asia, reports suggest there are predominant models of psychosocial stress (Tirupati & Thara, 2001), or a combination of illness beliefs (Shah et al., 2019; Naeem et al., 2016a; Saravanan et al., 2008). This is partly supported by the current findings. Participants in this study recalled initially holding a spiritual explanation for their experiences (such as '*nazar', 'taweez', 'Jinns', 'black magic' or 'possession')*, indicating it was a default belief and one not initially in line with a Eurocentric conceptualisation of FEP. Interestingly, for some there was a sense of shame associated with a spiritual framework, a finding that does not appear to be reported elsewhere. Variation in findings could be due to the impact of the sociocultural context, differences in MH systems, and length of time with services. As participants in this study were experiencing FEP and had not accessed EIS before, it is possible that their initial explanatory models were more in line with their cultural norms and values. It is also possible that having an indigenous label and/or explanatory model acted as a protective factor from internalised and experienced forms of stigma. For example, in this study for some, spiritual models were associated with attribution to a malicious external force rather than a personal deficit or failure.

However, it appears that interaction with EIS meant socialisation to that service's model of understanding, and to the language that the service uses to describe psychosis experiences.

Participants' experiences suggest that certain models of psychosis are prioritised in services. It seems as though un/knowingly services are imposing definitions and explanations, that are not fully considerate of cultural norms and beliefs.

In line with previous research (Dutta et al., 2019; Carter et al., 2017; Bhikha et al., 2015; Bhikha et al., 2012), this study also found that individuals held multiple explanations for experiences. However, to the best of the author's knowledge, this is the first study to demonstrate the *way* different explanatory models interact with more dominant conceptualisations and *how* this influences help-seeking, illness experiences and recovery in British SA individuals. Participant accounts were characterised by doubt and dispute and there appeared to be a temporal and recursive nature to sense-making when more than one explanation is present. Furthermore, the influence of multiple cultural normative beliefs and values creates a complex and dynamic process.

This study demonstrates that SA people's personal explanatory models related to their ethnicity or culture may intersect with more dominant Eurocentric models used in services, and that they cannot be easily integrated, so that people are challenged with navigating multiple models. For some participants there was wrestling between models, whilst for others it led to the rejection of one model over another (in these cases the health model provided by EIS staff was accepted over initial spiritual explanations). Mirza et al. (2019) also reported that over time spiritual beliefs reduced and were replaced by Eurocentric models of MH. Furthermore, the explanatory models of the clinician have been reported to influence the service user's own beliefs (Lebowitz & Ahn, 2014), which perhaps explains the findings in this study.

However, some participants felt that EIS did not always value a spiritual explanation to the same extent as the dominant psychobiosocial model. This echoes an earlier study by Islam et al. (2015) which reported that individuals from BAME groups find it difficult to discuss spiritual beliefs with EIS staff due to fear of judgement. In this study it was also found that SA service users were reticent to share their spiritual explanations with EIS staff due to a sense of embarrassment associated with this model, not feeling they would be believed or understood, or feeling that sharing this explanation would be associated with being 'unwell'. Interestingly, some participants recalled not sharing their explanatory model

because they were not asked and spoke of the impact of not having a shared ethnicity with their HCPs. However, ethnic matching between service users and HCPs has been reported to be both helpful and a hinderance (Prajapati & Liebling, 2021), and further research is needed to explore this.

Another novel finding, is that participants recollected various forms of *'testing and identifying proof'* for explanations. For some, there were indications of confirmatory bias, such as explanations based on the content of the voices or outcomes of rituals (see 'Testing and proof of illness beliefs' subtheme) or pre-existing beliefs (see 'A default belief of taweez' subtheme). In some instances it seems that explanations were reinforced by the relief that came with the knowledge that the experiences are common or shared and, for spiritual explanations, preventative and curable.

Participants described two types of maintaining factors: those that result in obtaining of confirmatory evidence (for example, Salma describing repeatedly being pushed off the prayer mat) and those that lead to disconfirmation of evidence (medication not working). Maintaining factors have been reported in the context of delusions (Freeman et al., 2002). This study suggests there is analogous process for how explanations are developed and maintained within a cultural context. There is potential here to normalise confirmation bias processes to help people understand their methods of testing and identifying proof. Professionals can be attentive to the service user's perspective, and not solely privilege the dominant model and undermine the service user's attempts at working within their own cultural norms.

Participants felt that the nature of the experiences, it being their responsibility to explore and work with multiple explanations, and the wider cultural context has left them *'feeling overwhelmed and resigned'*. This study partially supports Corin et al's (2005) assertions of convergence in family and service user experience of illness beliefs. However, some participants in this sample reported that there was divergence in explanatory models within families, which impacted on-going sense-making and help-seeking. This dissonance also appeared to a greater degree in sense-making of those experiencing psychosis and their family/ community and the MH system. Support or intervention based on spiritual explanations was therefore seen as separate and not in collaboration with formal services. A

similar finding was reported by Virdee et al. (2017), who described service users reporting that clinicians seemed open to hearing about different explanations, but not providing interventions in line with them.

All participants spoke of accessing informal support before, during and/or after formal support, similar to other reports (Beattie et al., 2020; Saleem et al., 2019; Dutta et al., 2019; Shah et al., 2019). These findings suggest services can play a more proactive role in engaging in wider explanations for FEP, beyond the models they are most aware of, and helping to support with interventions more in line with their service users' beliefs, e.g. further development and evaluation of culturally-adapted psychological therapies and increased awareness of other culture-specific intervention, such as prayer. This may help promote a more collaborative, holistic approach to understanding and supporting SA individuals experiencing FEP. BAME groups have a right to attain equity in mental healthcare without having to accept imposed Western values and beliefs.

Another important consideration in this population is based on the findings indicating '*A battle for identity*' in SA individuals experiencing FEP. Participants characterised their identity in the context of fragility, loss or conflict. For some there was a complex relationship with identity arising from their bicultural position in society, characterised by experiences of social exclusion and rejection (from both cultures), racism and trauma. It appears as though current MH services are not adequately accounting for cultural dimensions (role of family, religion and spirituality), risking further exclusion. It is important to note here, that in this study there were multiple intersections of stigmatised identities, such as race, ethnicity, gender and MH difficulties. Looking at these underlying intersections is an important way to increase equitable provision of care. Services can increase their cultural sensitivity, by moving beyond the illness to explore the identities of individual service users behind it and the impact of the historical, political and sociocultural context on experiences of distress.

Acculturation has been reported to be associated with improved quality of life in BAME service users experiencing schizophrenia (de Mamani et al., 2017), however it is also the responsibility of the host service to design a system that meets *their* needs. Accessing support from a system that was not designed to meet the needs of SA individuals, may also

be contributing to a sense of threat to cultural identity and could increase the risk of associating more strongly with an illness identity (Cicero et al., 2016). Rather than a risk of "double-stigma" (Gary, 2005), there appears a risk of "multiple-stigmas" associated with ethnicity and race, social standing and MH difficulties. For bicultural individuals, services should consider providing information about resources in the context of both the culture of origin and the host culture. For the former, this may include considering the benefits of cultural maintenance, and engaging with the community's traditions and practices, and for the latter it may mean providing transparent and accessible information about navigating the mental healthcare system. This may help to promote a sense of agency and empowerment, encourage social inclusion and help address the loneliness that appears to come with the experience of FEP in SA people (see 'Not belonging and identity', ' A broken identity' and 'Loneliness and rejection', 'Pervasive rejection' and 'Coping alone' subthemes).

In this study, there appeared to be the presence of a patriarchal family system and a gendered dimension to experiences; both appeared to impact on the perception of difficulties/distress and help-seeking. For example, Salma noted that if her father had believed her, her family would have reacted differently to her distress. Sophia, Sirah and Nazreen described their fathers taking charge of help-seeking. Asim, Dalil and Ismail described a patriarchal impact on expression of distress, pressure to minimise MH difficulties and fulfil gender roles tied to cultural norms. Here, it appears that the family, rather than the individual, is the basis of a social unit. This seems to be at odds with the MH system perspective of individualised support, suggesting that services need to give further consideration to working with a collectivist culture.

It is important to note, that the intention here is not to pathologise the cultural context of participants, but to increase our awareness and open up conversations about the impact of different cultures and working with different communities to facilitate cultural input and understanding.

Theme 3. Power and shame

Power and shame resonated deeply across participants' narratives, in the context of the experience of FEP itself, but also in relation to belonging to a SA community and accessing formal services. Three of the eight participants described a sense of empowerment via their psychosis related experiences (see '*Feeling empowered*' subtheme), a finding also reported by Luhrmann et al. (2015).

Resonating with the wider BAME literature (Akther et al., 2019; Newbigging & Ridley, 2018), feeling disempowered was a salient experience for all participants. For SA service users this appeared to be related to being dismissed, disbelieved and unheard or silenced. Some participants described power in the professional voice (being 'experts'), the MH system (e.g. to section) and professionals imposing power (e.g. medication compliance). This often meant the service user was in the position of disempowerment in their interactions with formal services. Services un/knowingly expecting service users to adopt a Eurocentric concept of psychosis will further continue to maintain feelings of powerless and alienation.

For many, if not all of the participants, disempowerment was mirrored in their interactions with family and the wider community, in terms of FEP experiences being dismissed as 'attention seeking', disbelieving of trauma experiences, and discouraging help-seeking from outside of the community. A relatively novel finding from this study is the degree to which one's social position in the SA community and wider context has on FEP experiences. The wider community appeared to hold a degree of power over the family's social standing and reputation and therefore their behaviour and response to family members experiencing FEP. These experiences of powerlessness, lack of control and agency mirrored interactions with formal services, and served to increase a sense of disempowerment and the right to exert one's agency in healthcare. For example, Salma described being at the mercy of her HCP, or Dalil who reported taking medication because he felt he had to comply, even though he did not want to.

Services can increase their awareness of how cultural norms and values may position the service user, and how this can then be mirrored by services and HCPs, by the inherent power and privilege that comes with belonging to the majority population and/or their

position in the mental healthcare system. Fay (2018) notes several ways in which current mental healthcare provision can demonstrate their colonising power that serves to confirm marginal and minority status, including, as demonstrated in this study, poor cultural acknowledgement, comprehension and adaptation.

This study indicates that SA individuals experiencing MH difficulties are at risk of intragroup marginalisation. For example, the experience of '*Hiding and being hidden*' was strongly reflected in participants' accounts (see '*Sharing, secrecy and shame*', '*Family as protective and isolating*', '*Wrestling with power and control*', '*Managing stigma and shame*', '*The frustration of feeling silenced*', '*Down-playing, self-censoring and stigma*' and '*Hiding and being hidden*' subthemes). All participants recollected instances of self or others 'brushing things under the carpet', being secretive, reframing difficulties as stress, anxiety or depression and not sharing experiences with friends or extended family. Some participants described what seemed to be family engaging in well-meaning approaches such as not disclosing difficulties or isolating them from the wider community (reducing contact with cousins, not attending family functions). Often this was done with the intention of mitigating social stigma and stigmatising labels. However, this served to increase feelings of isolation and perceiving oneself as being "ill" and 'abnormal', a finding reported by others (Rathod et al., 2010).

For some participants this led to a sense of mistrust in peers and the wider community, and some participants described choosing to withdraw and not disclose to avoid seemingly disingenuous others and being gossiped about. This was closely related to the family's social standing, and maintaining respect and honour within the community. Services may also be un/knowingly enforcing hiding things from others, by not expressing different explanations or acknowledging different ways we can conceptualise psychosis. Services can actively work with SA communities to encourage greater acceptance of MH difficulties and use family workers skilled in health promotion to help break the taboo of being open about MH concerns. This can also be via the promotion of recovery stories and encouraging the community to explore traditional and pluralistic help-seeking and support, alongside formal support if desired.

As previously noted, nomenclature can risk stereotyping, labelling and homogenising groups of highly diverse individuals (Corin et al., 2005). The findings of this study highlights the role of commonly-held group values such as collectivist values, cultural codes such as *"izzat"*, pluralistic help-seeking and religious and cultural beliefs and explanatory models. However, findings also suggest diversity and nuance in the lived experience. The discussion of these results, demonstrates the significant role of the socio-political structures in place that contribute to distress and perpetuate underutilisation of services, by marginalised groups due to inequitable healthcare and institutional racism. It highlights services have a long way to go in addressing cultural and institutional exclusion, including poor service provision for those not belonging to the majority White population and poor acknowledgement of specific needs, such as those related to ethnicity and culture (Fernando & Keating, 2008).

Services can acknowledge that social and cultural alienation alongside MH difficulties contribute to service users' attitudes, behaviours and experiences (Fay, 2018). Professionals can appreciate that previous experiences and community norms of secrecy or stigma can impact help-seeking, trust in HCPs and level of engagement. Intensive approaches may serve to retraumatise individuals, and make them more wary of the intentions of others in positions of power leading to further secrecy. These factors have to be considered in the context of the individual's experiences and their socio-cultural context. It is time to reconsider the historical label of 'hard to reach' applied to marginalised groups, and consider that it is the mental healthcare system that is *hard to reach.*

Key Findings

An IPA study was conducted exploring the lived experience of British SA individuals experiencing FEP, and how these experiences have been understood. Key findings are:

- Psychosis is characterised by a terrifying and uninvited intrusion and a fundamental shift in a sense of self.
- The process of sense-making is on a continuum: searching – in thick of it – reflecting.
- Conceptualisations of FEP are not initially aligned with a Eurocentric health model of psychosis.
- Ethnicity and culture play a key role in the experience itself, conceptualisations of FEP, self-concept and pluralistic help-seeking.
- SA service users are navigating a complex system of explanatory models, including identifying, understanding and working with multiple explanations, that are not always held by services.
- There is a recursive process of testing and identifying proof for explanations outside of service provision, often leaving people feeling lonely, resigned and overwhelmed.
- SA individuals experiencing MH difficulties are at risk of both inter- and intra-group marginalisation.
- Issues of power and shame are synonymous with the experience itself, interactions with the SA community and EIS.

Chapter 6

- Clinical Implications -

The following chapter will outline implications for practice, research and policy based on key study findings. Firstly, it will discuss clinical implications for professional practice and EIS teams; secondly, psychological support and working with multiple conceptualisation of psychosis in the SA community, and lastly, it will explore the role of clinical psychologists as leaders for change. Finally, a summary of the quality assurance process will be provided along with a critical review of the study.

Clinical Implications for Professional Practice

The findings from this study suggest that pathways into care and experiences when in services can be disempowering and (re)traumatising. Services may need to give further consideration to how the needs of SA individuals experiencing FEP are different, and make adaptations to engage better with the community they serve. This may involve using skilled outreach workers and providing high quality training (by those with lived experience and/or professionals) to other institutions (e.g. police and CJS) in working with MH difficulties and approaching vulnerable groups in different communities. In cases where there is a crisis presentation involving police, EIS teams can work collaboratively to help reduce feelings of coercion and threat. It has been suggested that one-off cultural sensitivity, unconscious bias or anti-racist training is insufficient to address institutional racism (Hart & Waddingham, 2018). Regular and on-going training is required, along with any institutions involved in MHA being held accountable to this and their ongoing actions (Hart & Waddingham, 2018). For professional practice, this may mean employing anti-racist champions or specialist cultural workers who work collaboratively with the SA community, those in leadership positions and across EIS teams to encourage and embed change systemically. Further research will be required to explore if proposed recommendations help or hinder and where gaps remain.

Clinical Implications for EIS teams

Despite the challenging condition EIS teams are operating within, it is clear that they are trying hard to uphold high standards of care. Participants described positive experiences of being cared for, advocacy and understanding. However, the findings from this study also highlight that there can be cultural dissonance between EIS teams and service users, which can impact access, engagement and alliance. Findings from this study advocate for further awareness/training in culturally relevant areas such as community discourses around psychosis. Furthermore, taking for granted that SA service users are aware of the spectrum of MH difficulties and conceptualise them the same way formal services do may pathologise distress and impede access and engagement. Similarly, in the recollection of experiences, it appeared participants were at different points on a continuum of the sense-making process. Where people are on this spectrum may impact the *way* in which they engage with services and their therapeutic relationship with EIS clinicians. For example, having an explanatory model for experiences may not be a priority, and the imposition of explanations or labels may alienate service users. Alternatively, a person's explanatory model may be the source of distress and require support.

Given the social positioning of SA service users, there is potential for EIS teams to give further consideration to the impact of the cultural context and how they can facilitate more autonomy. This could be by encouraging dialogue about prior interactions with other institutions or the mental healthcare system and acknowledge the impact that this has had and may have in the future. This may help to validate service users' experiences and encourage them to have autonomy in their care. Or services can increase choice of how people access the service (e.g. home/clinic/outside of immediate area) and who they are seen by (e.g. preferences related to gender, ethnicity or religion). Given the current workforce diversity issues in the NHS in general healthcare and mental healthcare – including clinical psychology - this may not always be feasible, but where possible should be offered. There is a pressing need for increasing ethnic and cultural diversity of clinical psychologists and mental healthcare staff to adequately represent the population it serves. Again, further research is required to explore the impact of ethnic matching between service user and clinician.

Clinicians can be more sensitive to community perceptions of formal intervention, for example being mindful of visible displays of ID during home visits (and the potential negative connotations) and being transparent about confidentiality. To help to try and minimise the risk of social exclusion, teams can work collaboratively with service users and their communities to help (re)build social networks and links to community support (e.g. religious or community centres) or signpost to support outside of EIS (e.g. hearing voices groups for marginalised groups).

Working with multiple concepts of psychosis

The findings from this study suggest that before entering formal services, SA individuals may hold a conceptualisation of psychosis in line with their interpersonal, religious and sociocultural beliefs and context. These do not appear to align with a Eurocentric concept of psychosis. However, in their interactions with EIS, it was largely felt that the spiritual explanations were felt to be less held and spoken about with HCPs. Those working therapeutically with SA service users, can take a more proactive role in asking about and exploring beliefs related to experiences, encourage discussion of the conflict that may arise between different ways of thinking about psychosis, respecting potential values (and potential difficulties) with each model.

As some participants described assigning power to professional opinion to help develop an understanding, discussion about conceptualisation can be flexible. For example, it may not be appropriate or useful when an individual is in crisis, but may be beneficial when this has settled and they can reflect on experiences and sense-making. Further research is needed to evaluate sense-making at different time points in psychosis related experiences, and advantages/disadvantages of this. Based on this study's results, despite the presence of an interacting system of explanations, service provision is yet to assimilate Western secular and religious/spiritual beliefs, and therefore appears to promote these ideas as mutually exclusive. There is potential for a bio-psycho-social-spiritual model of psychosis. However, further research is needed to explore this.

Only one participant in this study described an assimilated explanatory model of experiences, and this seems to have been developed independently of service provision. It is

possible that where there is a power imbalance at play, service users' conceptualisation may be particularly vulnerable to influence; and this may need to be given further consideration in marginalised populations that can be subjugated in multiple ways. Collaboratively, working with SA individuals and displaying genuine interest and curiosity may also somewhat mitigate/reduce stigma or non-disclosure of holding different explanations and conceptualisations of psychosis and allow more dialogue about accessing pluralistic resources outside of formal intervention. EIS can also consider wider dissemination of different conceptualisations of psychosis (leaflets, posters, information on websites) to highlight its contested, rather than definitive nature or set up groups where individuals can meet and explore multiple beliefs.

Spiritual explanations were often discussed in the context of providing hope and comfort as they were associated with beliefs that MH difficulties are preventable and curable. Clinicians can work sensitively with these ideas to maintain hope and agency, normalise different ways of thinking about psychosis and avoid a 'power over', paternalistic approach that may impact engagement, as demonstrated in this study. This means clinicians recognising their own knowledge and experience is culture specific and not universally applied (Helman, 2007). Also, that their position in the mental healthcare system affords them power and privilege, and may mean dominant explanations for psychosis are prioritised by them and taken as fact by service users as they are positioned as "experts" rather than appreciating that there are multiple conceptualisations.

Clinical psychologists are well placed to offer supervisory and/or reflexive support in EIS to consider the impact of Social Ggrraaacceeesss (SG) when working across multiple contexts (Burnham et al., 2008; Burnham, 2012; Roper-Hall, 1998, 2008). The acronym SG refers to the different identities that can constitute areas of social difference e.g. gender, geography, religion, race, age, ability, appearance, culture, class, education, ethnicity, employment, sexuality, sexual orientation and spirituality. However, these identities do not exist in isolation and intersect with one another, serving to increase power and/or subjugate. Intersectionality was first coined by Crenshaw (1989) and refers to the complex interaction of different types of discriminations that serves to oppress people via systemic injustice and social inequality (Butler, 2016).

In this study participants represented multiple marginalisations that intersected (e.g. race, ethnicity, gender, culture, class, spirituality) in addition to another label with potentially oppressive implications – as a 'person with FEP'. This study highlights the importance of services considering how structural power impacts these intersecting identities, and how they can operate to dismantle and challenge discourses. In MH support, equitable care means understanding racial disparities and not assuming everyone has the same needs, values and beliefs.

Intervention for SA service users

When considering appropriate intervention for minority groups, it is important to consider where the evidence for models and intervention comes from, who it is based on and crucially who is marginalised (see https://edisgroup.org/). Psychological theories and intervention have been criticised for disproportionately representing a WEIRD population (Western, Educated, Industrialised, Rich, Democratic) (Henrich et al., 2010), which may undermine culture specific explanations and privilege assessment, formulation and intervention grounded in individualism. Involving people from relevant communities in service evaluations, including design and outcomes is much needed.

Participants in this study were 2nd generation migrants. They were all born in the UK and appeared to maintain strong links with their country of origin via family, culture and community. However, navigating a bicultural identity presented several challenges, and risked both inter- and intra- group marginalisation. Professionals can discuss identity as part of the cultural formulation of experiences, and enquire into the cultural norms and values that may be impacting experiences. For example, Asim described the close-knit dynamics of his community, impacting his feelings of paranoia and Salma recalled '*izzat*' (family honour/respect) superseding help-seeking in her family interactions. Further consideration should be given to what it is like to be a part of this community, e.g. Salma's experience of prolonged domestic violence because of the need for the appearance of harmonious relationships and family cohesion/unity and keeping things within the family.

The findings of this study indicate that SA service users engage in pluralistic help-seeing and intervention prior to, during and after engagement with formal services. This highlights the

need for clinicians to increase their awareness and work in collaboration with those providing cultural and religious interventions. This could be done by developing strong community links with trusted religious or community figures to develop a mutual understanding of MH and help-seeking and adapt service provision to different communities (Agius et al., 2010).

Where psychological therapies have been adapted to work with presentations of psychosis, such as CBTp (Naeem et al., 2016b), and in ethnic minority groups (Naeem et al., 2015; Habibi et al., 2015), there is a risk that they minimise the lived realities of multiply-marginalised service users. Further research is required exploring how interventions are adopted and whether there are further approaches that might be useful. For example, Mir et al. (2015) has developed culturally adapted behavioural activation for the treatment of depression in Muslims, involving a values assessment, and if religion is an important value provision of a booklet with e.g. Muslim religious texts as part of the therapy.

Similar culture-specific interventions for psychosis may be beneficial and may also encourage a more holistic service provision e.g. prayer *and* formal intervention, rather than prayer *or* formal intervention, which may be harder for formal services to advocate, given relatively limited empirical evidence. Beyond such acute decisions, it might be beneficial, where possible, to discuss the usefulness of scientific approaches, e.g. to identify effective interventions (quantitative) and improve understanding regarding processes and meanings (qualitative), and their limitations (including culturally relevant ones), and to highlight the value of areas that are not part of science and which can be important in life, e.g. spiritual – i.e. considering multiple domains holistically and pluralistically. It is important for staff, service users, carers etc. to all have active collaborative input to any educational/dissemination projects.

Other approaches such as the PTMF (Johnstone & Boyle, 2018) or the Recovery model for psychosis (Leonhardt et al., 2020) that work *with* people's experiences in the context of adverse environments and trauma, acknowledging the cultural, relational, social and biological contexts, may be more appropriate. For example, participants in this study described the impact of trauma and violence committed against them leading to their experience of psychosis. Trauma experiences (personal and intergenerational) have been

associated with aetiology (inc. via epigenetics) (Pai et al., 2019; Mirza et al., 2019; Tahira & Agius, 2012; Cantor-Graae & Selten, 2005) and outcomes (Bailey et al., 2018) in psychosis. In offering therapeutic intervention such as trauma-informed therapy or EMDR, services may need to consider the risk of imposing Eurocentric approaches to distress. They may also want to consider other culturally diverse choices such as trauma-informed yoga (Justice et al., 2018). Although faith appeared to be a protective factor for some participants in this study, it did not seem as though it was specifically attended to as part of EIS intervention. HCPs can explore and provide interventions that give space to culture, religion and faith. Perhaps an issue here is that MH professionals often regard other interventions as lacking evidence of benefit, or potentially causing harm. This study strongly supports further research in culture-specific interventions and personally-relevant outcomes from a range of approaches.

In light of findings suggesting high levels of social isolation, loneliness and loss of social capital and social exclusion from the community, it may be prudent to consider the value of peer support. Puschner et al. (2019) are in the process of developing and evaluating a conceptual framework regarding Using Peer Support in Developing Empowering Mental Health Services (UPSIDES) – a programme advocating for the use of culturally appropriate peer support intervention. Along with encouraging the normalisation of psychosis related experiences in the SA population, peer support may also provide the opportunity to increase one's social network in the community, share experiences and resources, and tackle societal stigma. It may help empower service users and those experiencing diminished agency to critically examine common perceptions of HCPs as "experts" in *their* lived experience and sense-making. As some participants expressed concerns about confidentiality in the SA community, there may be other ways support can empower service users. For example, Lysaker et al. (2019) have developed metacognitive reflection and insight therapy (MERIT), used to jointly reflect on the lived experience to encourage agency and taking charge.

Although EIS are set-up to provide pharmacological and psychosocial intervention (including family intervention), it appears that it is not entirely how participants in this study understood the service. Participants described their interactions with EIS as largely around individual therapeutic intervention and did not describe any family involvement in EIS

support. There is potential for teams to facilitate further discussion of personal problems (including social and relational dimensions) alongside psychosis experiences and sense-making within the context of being a part of a SA community. Where EIS offer family intervention, this has to be sensitively approached and with an understanding of the impact of culture and ethnicity. Whilst providing general information about psychosis may be helpful, due to the difference in conceptualisations and the risk of societal stigma, it may be more prudent to encourage conversations about the impact of the experiences e.g. social exclusion. Along with developing the family's empathy, and moving away from blaming narratives (e.g. attention-seeking or drug and alcohol related), it may also encourage open conversations about psychosis.

The results of this study suggest that an individualistic approach and provision of psychoeducation about psychosis from a Eurocentric perspective may be alienating SA service users and threatening their cultural identity of collectivism. Olson et al. (2014) propose that services should try and encourage involvement of the service user's family and wider social network, to maintain these links through recovery and beyond. For example, Open Dialogue is a method that encourages seeing psychosis as happening between people, rather than within people (Seikkula et al., 2001). However, it is likely there are both intra- and inter-personal aspects in addressing psychosis. Open Dialogue is gaining momentum in the UK NHS, and an evidence base of its utility is growing (Hendy & Pearson, 2020; Freeman et al., 2019; Razzaque & Stockmann, 2016; Razzaque & Wood, 2015).

Clinical psychologists as leaders for change

Decolonising the MH system is complex and can mean many different things to different people, however it is the responsibility of every MH professional to play a part in this. Clinical psychologists are often in leadership positions, and as such are well placed to help encourage services and teams to consider if they are providing equitable care. Some ways they can implement change is via the provision of training, consultancy, supervision and MDT working. They can take a proactive role in encouraging the expansion of the conceptualisation of psychosis, thinking about issues of race and culture in MH practice, and ways in which the self and system operates to perpetuate inequitable service provision, and therefore ways this can be challenged e.g. via looking at service users through an

intersectional lens. This can be via the provision of reflective groups to explore how we can recognise and deconstruct taken for granted language (such as psychosis and paranoia) in our interactions with services users (Finlay, 2008). Clinical psychologists (along with other professionals) can advocate for SA service users to be offered paid work to come in and talk about and train HCPs about identity and its impact on their FEP experiences.

In line with other reports (Mann et al., 2014; Weatherhead & Daiches, 2010), participants in this study reported accessing MH support via their GP. HCPs – including clinical psychologists - can encourage services to engage in wider outreach work with GPs to increase awareness and knowledge of MH and intervention. This may involve improving awareness of services and referral pathways, provision of on-going training to equip GPs (and other professionals) with the skills and confidence to recognise and support different MH presentations, and/or holding in-person or virtual clinics to support with potential FEP presentations and experiences.

Clinical psychologists can encourage increasing the diversity in the workforce at all levels, promote the use of decolonising questions and challenge the academic and clinical systems that promote the conceptualisation of MH from one (Eurocentric) perspective. They can develop strong ties with communities and encourage research into community knowledge of lived experiences. However, this research should then be translated beyond academic literature into clinical practice. In teaching and training, clinical psychologists can critically approach the curriculum and literature, for example being transparent about the historical context of psychology and psychiatry, the cultural context in which MH is disproportionately based and the prevalence of Eurocentric models and theories. They can advocate for more SA service user/survivor- led groups and for these groups to be involved in decision-making and training future generations of practitioners.

Importantly, HCPs – including clinical psychologists – can also work actively with local SA communities. For example, via engagement through social events, services at faith based institutions (e.g. Mosques, Temples, Gurdwaras, Churches), community centres and with religious leaders, to promote MH awareness, how to access services and what is available. Clinical psychologists can have a key role beyond this, and can also advocate for marginalised groups via other networks promoting social change (e.g. Psychologists for

Social Change, International Society for Psychological and Social approaches to Psychosis UK [ISPS- UK], Islamic Psychology Movement (Skinner, 2019; Rothman & Coyle, 2018; Al-Karam, 2018).

Several clinical implications have been proposed. It is imperative that any changes and developments outlined above are rigorously evaluated to explore efficacy, refine practice (according to what works best for services users and staff) and identify cases where there are unintended adverse consequences of changes that make intuitive sense.

Implications for future research

This study used IPA to consider how SA individuals experience FEP, and make sense of these experiences. Given this area remains underexplored, significantly more funding is required to investigate the experience of psychosis in different SA groups, and critically the impact of historical, social and cultural factors that affect their experiences to increase theoretical transferability. This may be via using different researchers (with their own reflexivity), study participants and other services (e.g. inpatient units). In light of the results regarding working with multiple models, further research is needed to explore the process and trajectory of explanatory models, and if it impacts outcomes and recovery. Fernando (2017) suggests that the relatively disproportionate body of work exploring biomedical causes and pharmacological intervention, indicates the biomedical hegemony in the current mental healthcare system. Considerably more research is needed outside of these fields and exploring the systemic roots underlying the experience of FEP.

Despite EIS operating under a broad age margin (14-65) the majority of participants were in their twenties. Further research is required across the age-span, to capture different experiences of FEP e.g. SA parents experiencing FEP or those over 50. Furthermore, exploring experiences across different routes of access to care pathways and at different

points in SA people's experiences of psychosis (e.g. ARMS[6], prodromal phase) would add further insight.

This study did not examine DUP. Evidence of ethnic differences in DUP is equivocal, and further research is needed to gain insight. The current qualitative findings, indicate that further mixed methods research may prove valuable. Furthermore, due to its exploratory aims, a more focused sample was not used; future research could explore the experience across the gender spectrum (to identify similarities and differences), or Indian *or* Bangladeshi *or* Pakistani individuals experiencing FEP. The participants in this sample were not a homogenous group, even though they all self-identified as belonging to a SA ethnic minority group. Much more research is needed to explore the experiences within and between different communities under this broad category. For example, only one participant self-ascribed to a British Bangladeshi ethnicity, despite this group being the second largest South Asian group accessing the EIS in which this study was conducted (see Table 1).

Lastly, given the discussion on the impact of intersectionality, further research is required on other types of identity that may make SA individuals more vulnerable to discrimination and subjugation (e.g. gender, sexuality, appearance) in their interactions with the mental healthcare system. This study explored the lived experience of psychosis, but acknowledges that experiences have interpersonal aspects. Further research is needed exploring the perspectives and experiences of the people within systems that include SA service users, such as family and community members, professionals involved in care (informal, primary, secondary and tertiary) and other institutions, such as police and CJS. There is potential to extend the current work and use IPA to explore staff experiences of working with people from cultural groups other than their own and/or with different conceptualisations of psychosis. More research is also needed to investigate the perspectives of policy-makers and commissioners regarding service provision for marginalised groups.

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[6] At Risk Mental State Services (ARMS) work with young people and adults to help prevent or delay the development of FEP.

Implications for policy

This study suggests SA individuals experiencing FEP hold multiple explanatory models and reside in a collectivist culture. However, the EIS they access is underpinned by a dominant Eurocentric conceptualisation of psychosis reinforced by individualistic values and norms. Policy and service planning and delivery can play a key role in addressing this and wider disparities that exist between the service provision to White majority and marginalised groups. An initial action is to prioritise the lived experience as informative in decision-making processes. This means acknowledging that the experience of MH difficulties and sense-making is impacted by intersecting identities including race, ethnicity and cultural identity. A consequence is that there is no one-size fits all conceptualisation of distress and therefore MH provision. Policies need to address the fragmented provision of healthcare across services and how this puts marginalised groups disproportionately at risk of 'falling through the cracks'. Furthermore, policies need to be re-evaluated to examine if they truly address the structural inequalities at service level, and if and how these policies are being translated to race equity in local services (Salway et al., 2016).

Broader policy changes need to occur that recognise and address the impact of socio-political processes such as racism and discrimination, socioeconomic inequalities and the challenges faced by those occupying multiple cultural identities and marginalised groups. This can be via initiatives and policies that are anti-racist and trauma-informed and that acknowledge that FEP is a response to challenging lived experiences. This means including those with lived experience in decision-making and policy and service development. Furthermore, it means demanding policy development that includes preventative aspects rather than reactive, and actively addresses psychological and social factors that contribute to MH difficulties (e.g. poverty, discrimination, abuse, unemployment) (Wilkinson & Pickett, 2010). Those in leadership positions – including clinical psychologists – can contribute to think tanks, develop and contribute to working groups and taskforces challenging issues of race and culture in MH.

Lastly, given the recent controversial report by the Commission on Race and Ethnic Disparities (CRED, 2021), it is clear that it is vital for UK governing bodies to demonstrate

absolute transparency in policy development and government led reports that investigate these issues.

Study Strengths

Credibility and Validity

To further ensure credibility and validity in the research process, guidelines by Yardley (2000) were adopted. To ensure sensitivity the theoretical context in which the research sits was examined and a comprehensive scoping review of the literature was conducted. The researcher was aware of the inherent power balance in the interview context and took time at the start to build rapport, make the participant as comfortable as possible and strived for the study to be led by them. Participants were encouraged to use their own language for their experiences e.g. not using the term psychosis, if they did not say it, and being transparent about the purpose of this study i.e. for qualification.

In order to demonstrate commitment and rigour to the research process, the author has made the fullest attempt to demonstrate transparency in the analysis process, interpretations and illustration of findings. Full effort has been made to ensure the participants voice is at the forefront, via the inclusion of extracts of participants' accounts. Lastly, the impact of the study is demonstrated via the findings and subsequent discussion which captures the lived experience of psychosis in SA individuals. Based on the findings, effort was made to discuss practical implications applicable at multiple levels including, SA service users, clinical practice, policies and future research. To ensure wider impact there are plans to disseminate the findings within the host trust, to both staff and service users and in a peer-reviewed paper.

Recommendations stipulated by Elliot et al. (1999) were adopted to ensure the research was of sufficient quality (appendix XI), including a research journal of reflections (appendix XII).

Study Limitations

Participant Sample

It is possible that there was a bias in who was selected by the gatekeepers and who agreed to take part in the study, which may impact the research's credibility. Those who chose to take part may have been: those most interested in discussing the study topic, were in less distress in relation to their experiences, or those who had a more positive relationship with the gatekeeper or EIS. Contributions from those individuals who did not have the above experiences is much needed.

Other limitations of the population sample are around issues regarding gender, ethnicity, race, culture and language. As discussed earlier, there are limitations associated with the heterogeneity of the category of South Asian. The majority of the sample identified as British Pakistani. Recruitment for research in the British SA population has been noted as a challenge, and certain communities remain particularly underrepresented (e.g. Bangladeshi) (Waheed et al., 2020; Quay et al., 2017). This sample consisted of 2nd generation SA individuals; further research is needed to explore experiences of FEP in other generations of SA individuals.

The decision to keep the criteria broad and include all genders was based theoretically on the lack of research in this group on their experiences of FEP and sense-making, and pragmatically to improve the ease of recruitment and access to participants. This study also stipulated an exclusionary criteria of non-English speakers – this served to exclude those individuals perhaps from 1st generation, where English may not be their first language or people who may not be confident in conversing in English. This decision was based on the study methodology (IPA). However, by doing this the voices of others may have also been excluded (e.g. those with refugee or asylum-seeking status). By not taking into account the experiences of SA individuals who do not communicate primarily in English, this study may reflect wider inequalities and inequities to care present in services for these groups. However, despite these limitations, this does not invalidate the accounts of the participants who did take part.

Study criteria may also inadvertently perpetuate the idea that SA individuals form a homogenous group of people, just as many policies and services, within the NHS and beyond, refer to 'BAME groups' collectively. This may serve to problematically imply that all non-White groups have the same needs and are impacted by structural discrimination and racism in the same way. Whilst Indian, Bangladeshi and Pakistani individuals, and those across the gender spectrum may have similar experiences of being impacted by racialised discourses, they may hold different social positions. Although this study did endeavour to recruit an equal number from each 'ethnic' group, all but one participant self-identified as British Pakistani. There were more participants who self-ascribed as 'female' than 'male' and only one participant was non-binary. These individuals' experiences may be more represented in the findings.

Study Design

This study used cross-sectional semi-structured interviews to gather data. Accounts therefore often relied on retrospective recollection of experiences, often of a distressing and confusing nature. Although longitudinal observation may have potentially offered more opportunity to explore sense-making, this would not have been feasible due to time. Furthermore, given the nature of the topic it did not feel ethical or necessary. As discussed in Chapter 2, focus groups were considered, as they may have allowed for a more comfortable setting, validation of experiences and a sense of empowerment. However, there are issues of confidentiality and there is potential that it may have restricted some participants' confidence to speak openly, share ideas about conceptualisation of psychosis without feeling judged or share trauma experiences.

After careful reflection IPA was deemed the most appropriate method to explore the lived experience of psychosis. However, IPA relies on language to infer subjective reality, and the words participants' choose to describe experiences constructs a particular version of experiences. It is likely that a single event can be described in multiple ways and this study represents one version.

Service Users/Participant Involvement

This study's research proposal was shared with one service user group and the Leeds HEER group, before data collection began. However, the research did not have any active service user involvement beyond this. Further input would have most certainly offered a valuable contribution, however due to difficulties in the recruitment process this was not feasible. Ideally, experts-by-experience should be included in all stages of the research. However, due to the academic requirements, the planning and degree of commitment required by the researcher and service users this was not feasible for this project. Future short-scale academic work should consider how meaningful co-production can be facilitated.

Due to the nature of the analysis process, which requires extensive interpretation by the researcher through their experience, theoretical frameworks and lens, it is possible that participants may not clearly recognise their account. Morse (2015) suggests that in a study of this design the researcher can be considered the best judge of the analytical findings. However, member-validation would have further enhanced the credibility of this research. Again, due to time restrictions, this was not undertaken, until after submission of the thesis.

Closing reflections

This study was more of a challenge than I anticipated. Surprisingly, for the most part this was not related to the impact of the COVID-19 pandemic, although there likely will have been an impact on recruitment and interviews. Whilst I was expecting some things to come up (e.g. social stigma, illness beliefs related to religion or spirituality), I was surprised by the sense of shame associated with them and how although they seemed to be default beliefs, they were perceived to be the alternative way of interpreting their lived experiences. I also didn't expect to see the process people go through when there are multiple models held. I wondered what influence my ethnicity and dual role as a clinician/researcher had, and if they held assumptions about what I believed which impacted their disclosure.

A significant challenge was the analysis and write-up process, and balancing description of accounts and more abstract interpretation. For some narratives, depth of analysis seemed harder to achieve and although lots of interesting avenues were offered, this made me feel

like my synthesis of these accounts was more limited than others. Hearing each story and wanting to respect the time and emotional effort of recounting them for me made a significant contribution to my choice to include both an individual and group analysis in the final write-up. However, this became more stressful than anticipated because of the word count restriction for a DClinPsy thesis.

I expected that my assumptions would be challenged and I would learn things I was not expecting to, and I am pleased to say this was the case. Final thoughts that I have been left with are, who have I missed? Who remain the unheard voices?

Conclusions

To summarise, this study sought to provide a voice to a population under- represented and explored in the literature, via investigating the lived experience and sense-making of British South Asians experiencing FEP and accessing EIS. Psychosis was characterised as a terrifying and uninvited intrusion, a fundamental shift in sense of self and disconnection. Distinctive ethnic and cultural influence was identified on self-concept, conceptualisation of psychosis and working with multiple frameworks, some not always favoured by services. In addition, experiences were contextualised under power and shame, and this research proposes that socio-cultural/political context and racialised discourses within this, have an impact not only on the aforementioned, but also in the experience of help-seeking from informal and formal services, and *how* services help them. This study identifies that there is a role for psychology to challenge current discourses and service provisions and create meaningful service-user led change to increase equitable provision of mental healthcare in the UK. Collectively, this work highlights that the mental healthcare system is yet to adequately adapt to reflect the population it proports to support. However, before meaningful change can happen for the SA community, much more research is needed to explore *why* we need to adapt, *how* we adapt and *whom* we are adapting for.

- References -

Abdulla, M. R. (2018). Culture, religion, and freedom of religion or belief. *The Review of Faith & International Affairs*, *16*(4), 102-115.

Al-Karam, C. Y. (2018). Islamic psychology: Towards a 21st century definition and conceptual framework. *Journal of Islamic Ethics*, *2*(1-2), 97-109.

Agius, M., Talwar, A., Murphy, S., & Zaman, R. (2010). Issues regarding the delivery of early intervention psychiatric services to the South Asian population in England. *Psychiatria Danubina, 22*(2), 266-269.

Ahmad, I., Khalily, M. T., & Hallahan, B. (2017). Reasons associated with treatment non-adherence in schizophrenia in a Pakistan cohort. *Asian Journal of Psychiatry, 30*, 39-43.

Akther, S. F., Molyneaux, E., Stuart, R., Johnson, S., Simpson, A., & Oram, S. (2019). Patients' experiences of assessment and detention under mental health legislation: systematic review and qualitative meta-synthesis. *BJPsych Open*, *5*(3), e37, 1-10.

Albert, N., Melau, M., Jensen, H., Hastrup, L. H., Hjorthøj, C., & Nordentoft, M. (2017). The effect of duration of untreated psychosis and treatment delay on the outcomes of prolonged early intervention in psychotic disorders. *NPJ Schizophrenia, 3*(1), 34-34.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th Edition). Washington, DC.

Anderson, K. K., Flora, N., Archie, S., Morgan, C., & McKenzie, K. (2014). A meta-analysis of ethnic differences in pathways to care at the first episode of psychosis. *Acta Psychiatrica Scandinavica, 130*(4), 257-268.

Bahl, V., (1999). Mental illness: A national perspective. In Bhugra, D. & Bahl, V. (Eds.) *Ethnicity: An Agenda for Mental Health*, pp. 7-22. London, UK: Gaskell: The Royal College of Psychiatrists.

Bailey, T., Alvarez-Jimenez, M., Garcia-Sanchez, A. M., Hulbert, C., Barlow, E., & Bendall, S. (2018). Childhood trauma is associated with severity of hallucinations and delusions in psychotic disorders: a systematic review and meta-analysis. *Schizophrenia Bulletin*, *44*(5), 1111-1122.

Baker C. (2020) *Mental health statistics for England: prevalence, services and funding. Briefing Paper Number 6988*. Retrieved from: https://researchbriefings.files.parliament.uk/ documents/SN06988/SN06988.pdf. Accessed 24th March 2020.

Barnett, P., Mackay, E., Matthews, H., Gate, R., Greenwood, H., Ariyo, K., ... & Smith, S. (2019). Ethnic variations in compulsory detention under the Mental Health Act: a systematic review and meta-analysis of international data. *The Lancet Psychiatry*, *6*(4), 305-317.

Beattie, C., Ritchie, F., Cardno, A., Mahmood, T. (2020). Migration and Psychosis: Evidence from South Asian Communities in Bradford. *The Journal of Islamic International Medical College, 15*(4), 226-230.

Berg, A. O., Aas, M., Larsson, S., Nerhus, M., Hauff, E., Andreassen, O. A., & Melle, I. (2015). Childhood trauma mediates the association between ethnic minority status and more severe hallucinations in psychotic disorder. *Psychological Medicine*, *45*(1), 133-142.

Bergström, T., Seikkula, J., Holma, J., Mäki, P., Köngäs-Saviaro, P., & Alakare , B. (2019). How do people talk decades later about their crisis that we call psychosis? A qualitative study of the personal meaning-making process. *Psychosis*, *11*(2), 105-115.

Bertelsen, M., Jeppesen, P., Petersen, L., Thorup, A., Ohlenschlaeger, J., le Quach, P., . . . Nordentoft, M. (2008). Five-year follow-up of a randomized multicenter trial of intensive early intervention vs standard treatment for patients with a first episode of psychotic illness: the OPUS trial. *Archives of General Psychiatry, 65*(7), 762-771.

Berry, J. W. (2005). Acculturation: Living successfully in two cultures. *International Journal of Intercultural Relations*, *29*(6), 697-712.

Bhikha, A. G., Farooq, S., Chaudhry, N., & Husain, N. (2012). A systematic review of explanatory models of illness for psychosis in developing countries. *International Review of Psychiatry*, *24*(5), 450-462.

Bhikha, A.G., Farooq, S., Chaudhry, N., Naeem, F., & Husain, N. (2015). Explanatory models of psychosis amongst British South Asians. *Asian Journal of Psychiatry*, *16*, 48-54.

Bhui, K., & Bhugra, D. (2002). Mental illness in Black and Asian ethnic minorities: Pathways to care and outcomes. *Advances in Psychiatric Treatment*, *8*(1), 26-33.

Birchwood, M., & Chadwick, P. (1997). The omnipotence of voices: testing the validity of a cognitive model. *Psychological Medicine*, *27*(6), 1345-1353.

Bleuler, E. (1950). *Dementia Praecox or the Group of Schizophrenias*. New York, US: International Universities Press.

Bradford District Care NHS Foundation Trust. (2020). *Equality, Diversity and Inclusion Annual Report.* [online] Retrieved from: https://www.bdct.nhs.uk/. Accessed 2nd June 2021.

British Psychological Society (2018). *Code of Ethics and Conduct*. [online] Leicester, UK: The British Psychological Society. Retrieved from: https://www.bps.org.uk/sites/bps.org.uk/files/Policy%20-%20Files/Code%20of%20Ethics%20and%20Conduct%20(2018).pdf. Accessed 12th August 2019.

British Psychological Society (2018). The Power Threat Meaning Framework. [online] Leicester, UK: The British Psychological Society. Retrieved from: https://www.bps.org.uk/sites/bps.org.uk/files/Policy%20-%20Files/PTM%20Main.pdf. Accessed 3rd February 2020.

Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, *21*(1), 87-108.

Bourque, F., van der Ven, E., & Malla, A. (2011). A meta-analysis of the risk for psychotic disorders among first- and second-generation immigrants. *Psychoogical Medecine, 41*(5), 897-910.

Bowker, G. C., & Star, L. S. (1999). *Sorting things out: classification and its consequences.* Cambridge, US: MIT Press.

Brunet, K., Birchwood, M., Lester, H., & Thornhill, K. (2007). Delays in mental health services and duration of untreated psychosis. *Psychiatric Bulletin, 31*(11), 408-410.

Burman, E., Chantler, K., & Batsleer, J. (2002). Service responses to South Asian women who attempt suicide or self-harm: challenges for service commissioning and delivery. *Critical Social Policy*, *22*(4), 641–668.

Burnham, J., Alvis, D., Whitehouse, L. (2008) Learning as a context for differences and differences as a context for learning. *Journal of Family Therapy*, 30(4), 529-542.

Burnham, J. (2012). Developments in Social GRRRAAACCEEESSS: visible – invisible and voiced – unvoiced. In Krause, I.-B. (Ed.) *Culture and Reflexivity in Systemic Psychotherapy: Mutual Perspectives,* pp. 139-160. London, UK: Karnac.

Burns, J. K., & Esterhuizen, T. (2008). Poverty, inequality and the treated incidence of first-episode psychosis. *Social Psychiatry and Psychiatric Epidemiology, 43*(4), 331-335.

Butler, C. (2016). Intersectionality in family therapy training: inviting students to embrace the complexities of lived experience. *Journal of Family Therapy*, 37(4), 583-589.

Carr, W. (1995). *For Education - Towards Critical Educational Inquiry*. Buckingham, UK: Open University Press.

Cantor-Graae, E., & Selten, J. P. (2005). Schizophrenia and migration: a meta-analysis and review. *Americal Journal of Psychiatry, 162*(1), 12-24.

Cardno, A. G., & Owen, M. J. (2014). Genetic relationships between schizophrenia, bipolar disorder, and schizoaffective disorder. *Schizophrenia Bulletin, 40*(3), 504-515.

Carter, L., Read, J., Pyle, M., & Morrison, A. P. (2017). The impact of causal explanations on outcome in people experiencing psychosis: A systematic review. *Clinical Psychology & Psychotherapy*, *24*(2), 332-347.

Carter, L., Read, J., Pyle, M., Law, H., Emsley, R., & Morrison, A. (2018). Causal beliefs in people experiencing psychosis: The relationship to treatment accessed and the perceived helpfulness of treatment. *Psychology and Psychotherapy: Theory, Research and Practice*, *91*(3), 332-344.

Chamberlain, K., Murray, M., Willig, C., & Rogers, W. S. (2008). Health Psychology. In Willig, C. & Rogers, S. W. (Eds.) *The Sage handbook of qualitative research in psychology*, pp. 390-406. London, UK: Sage publications.

Chakraborty, K., Das, G., Dan, A., Bandyopadhyay, G., & Chatterjee, M. (2013). Perceptions About the Cause of Psychiatric Disorders and Subsequent Help Seeking Patterns Among Psychiatric Outpatients in a Tertiary Care Centre in Eastern India. *German Journal of Psychiatry*, *16*(1), 7-15.

Chernomas, W. M., Rieger, K. L., Karpa, J. V., Clarke, D. E., Marchinko, S., & Demczuk, L. (2017). Young women's experiences of psychotic illness: a systematic review of qualitative research. *JBI Evidence Synthesis*, *15*(3), 694-737.

Chew-Graham, C., Bashir, C., Chantler, K., Burman, E., & Batsleer, J. (2002). South Asian women, psychological distress and self-harm: lessons for primary care trusts. *Health and Social Care Community, 10*(5), 339-347.

Choudry, A., & Farooq, S. (2018). Psychosis and related disorders in international classification of Disease-11 and their relationship to diagnostic and statistical Manual-5 and international classification of Disease-10. *Indian Journal of Social Psychiatry, 34*(5), 11-16.

Cicero, D. C., Martin, E. A., Becker, T. M., & Kerns, J. G. (2016). Decreased self-concept clarity in people with schizophrenia. *The Journal of Nervous and Mental Disease*, *204*(2), 142.

Connor, C., Greenfield, S., Lester, H., Channa, S., Palmer, C., Barker, C., Lavis, A. and Birchwood, M. (2016) Seeking help for first-episode psychosis: a family narrative. *Early Intervention in Psychiatry*, 10, 334-345.

Commander, M., Cochrane, R., Sashidharan, S., Akilu, F., & Wildsmith, E. (1999). Mental health care for Asian, black and white patients with non-affective psychoses: pathways to the psychiatric hospital, in-patient and after-care. *Social Psychiatry and Psychiatric Epidemiology, 34*(9), 484-491.

Commission on Race and Ethnic Disparities: The Report (2021). Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/974507/20210331_-_CRED_Report_-_FINAL_-_Web_Accessible.pdf. Accessed 19th May 2021.

Corin, E., Thara, R., & Padmavati, R. (2005). Shadows of culture in psychosis in south India: A methodological exploration and illustration. *International Review of Psychiatry*, *17*(2), 75-81.

Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. *University of Chicago Legal Forum*: Article 8(1). Retrieved from: https://chicagounbound.uchicago.edu/cgi/viewcontent.cgi?article=1052&context=uclf Accessed 12th May 2021.

Davidson, L., Shahar, G., Stayner, D. A., Chinman, M. J., Rakfeldt, J., & Tebes, J. K. (2004). Supported socialization for people with psychiatric disabilities: Lessons from a randomized controlled trial. *Journal of Community Psychology*, *32*(4), 453-477.

Degnan, A., Berry, K., James, S., & Edge, D. (2018). Development, validation and cultural-adaptation of the knowledge about psychosis questionnaire for African-Caribbean people in the UK. *Psychiatry Research*, *263*, 199-206.

Dennick, L., Fox, A. P., & Walter-Brice, A. (2013). Mindfulness groups for people experiencing distressing psychosis: An interpretative phenomenological analysis. *Mental Health Review Journal*, *18*(1), 32-43.

De Haan, A. M., Boon, A. E., de Jong, J. T., Hoeve, M., & Vermeiren, R. R. (2013). A meta-analytic review on treatment dropout in child and adolescent outpatient mental health care. *Clinical Psychology Review*, *33*(5), 698-711.

De Haan, A. M., Boon, A. E., de Jong, J. T. V. M., & Vermeiren, R. R. J. M. (2018). A review of mental health treatment dropout by ethnic minority youth. *Transcultural Psychiatry*, *55*(1), 3-30.

de Mamani, A. W., Weintraub, M. J., Maura, J., de Andino, A. M., Brown, C. A., & Gurak, K. (2017). Acculturation styles and their associations with psychiatric symptoms and quality of life in ethnic minorities with schizophrenia. *Psychiatry Research*, *255*, 418-423.

Department of Health (2005) *Delivering race equality in mental health care*. London, UK. Retrieved from: research.bmh.manchester.ac. uk/ReACH/resources/keypaper4.pdf. Accessed 14th June 2019.

Department of Health (2008) Mental Health Act 1983. London, UK: The Stationery Office. Retrieved from: https://www.legislation.gov.uk/ukpga/1983/20/contents/enacted. Accessed 5th April 2021.

Department of Health (2008). Code of Practice: Mental Health Act 1983. London, UK: The Stationery Office. Retrieved from: https://www.legislation.gov.uk/ukpga/1983/20/contents. Accessed 5th April 2021.

Department of Health (2010) *Race Equality Action Plan: a five year review*. London, UK. Retrieved from: http://data.parliament.uk/DepositedPapers/Files/DEP2014-0975/PQ202552_PQ202500_-_Report.pdf. Accessed 19th April 2021.

DeRosse, P., & Karlsgodt, K. H. (2015). Examining the Psychosis Continuum. *Current Behavioral Neuroscience Reports, 2*(2), 80-89.

Dein, S., & Sembhi, S. (2001). The Use of Traditional Healing in South Asian Psychiatric Patients in the U.K.: Interactions between Professional and Folk Psychiatries. *Transcultural Psychiatry, 38*, 243 - 257.

Drake, R. J., Haley, C. J., Akhtar, S., & Lewis, S. W. (2000). Causes and consequences of duration of untreated psychosis in schizophrenia. *The British Journal of Psychiatry*, *177*, 511–515.

Drake, R. J., Husain, N., Marshall, M., Lewis, S. W., Tomenson, B., Chaudhry, I. B., Everard, L., Singh, S., Freemantle, N., Fowler, D., Jones, P. B., Amos, T., Sharma, V., Green, C. D., Fisher, H., Murray, R. M., Wykes, T., Buchan, I., & Birchwood, M. (2020). Effect of delaying treatment of first-episode psychosis on symptoms and social outcomes: a longitudinal analysis and modelling study. *The Lancet Psychiatry*, *7*(7), 602–610.

Dunkley, J. E., Bates, G. W., & Findlay, B. M. (2015). Understanding the trauma of first-episode psychosis. *Early Intervention in Psychiatry*, *9*(3), 211-220.

Dutta, M., Spoorthy, M. S., Patel, S., & Agarwala, N. (2019). Factors responsible for delay in treatment seeking in patients with psychosis: A qualitative study. *Indian Journal of Psychiatry, 61*(1), 53-59.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*(3), 215-229.

Fay, J. (2018). Decolonising mental health services one prejudice at a time: psychological, sociological, ecological, and cultural considerations. *Settler Colonial Studies*, *8*(1), 47-59.

Fearon, P., & Morgan, C. (2006). Environmental factors in schizophrenia: the role of migrant studies. *Schizophrenia Bulletin, 32*(3), 405-408.

Fearon, P., Kirkbride, J. B., Morgan, C., Dazzan, P., Morgan, K., Lloyd, T., ... & Mallett, R. (2006). Incidence of schizophrenia and other psychoses in ethnic minority groups: results from the MRC AESOP Study. *Psychological Medicine*, *36*(11), 1541-1550.

Fernando, S., & Keating, F. (Eds.). (2008). *Mental health in a multi-ethnic society: A multidisciplinary handbook*. London, UK: Routledge.

Fernando, S. (2017). *Institutional racism in psychiatry and clinical psychology*. London, UK: Palgrave Macmillan.

Finlay, L. (2008). Reflecting on 'Reflective practice'. Practice-based Professional Learning, Paper 52. UK: The Open University. Retrieved from: http://oro.open.ac.uk/68945/1/Finlay-%282008%29-Reflecting-on-reflective-practice-PBPL-paper-52.pdf. Accessed 4th January 2021.

Fisher, H. L., Jones, P. B., Fearon, P., Craig, T. K., Dazzan, P., Morgan, K., ... & Murray, R. M. (2010). The varying impact of type, timing and frequency of exposure to childhood adversity on its association with adult psychotic disorder. *Psychological Medicine*, *40*(12), 1967-1978.

Fitzpatrick R, Kumar S, Nkansa-Dwamena O, Thorne L. (2014) *Ethnic inequalities in mental health: promoting lasting positive change*. Retrieved from: https://lankellychase.org. uk/wp-content/uploads/2015/07/Ethnic-Inequality-in-Mental- Health-Confluence-Full-Report-March2014.pdf. Accessed 24th April 2020.

Freeman, D., Garety, P. A., Kuipers, E., Fowler, D., & Bebbington, P. E. (2002). A cognitive model of persecutory delusions. *British Journal of Clinical Psychology*, *41*(4), 331-347.

Freeman, A. M., Tribe, R. H., Stott, J. C., & Pilling, S. (2019). Open dialogue: a review of the evidence. *Psychiatric Services*, *70*(1), 46-59.

Fusar-Poli, P., Radua, J., McGuire, P., & Borgwardt, S. (2012). Neuroanatomical maps of psychosis onset: voxel-wise meta-analysis of antipsychotic-naive VBM studies. *Schizophrenia Bulletin, 38*(6), 1297-1307.

Gary, F. A. (2005). Stigma: Barrier to mental health care among ethnic minorities. *Issues in Mental Health Nursing*, *26*(10), 979-999.

Gergen, K. J. (1977). Stability, change, and chance in understanding human development. In Datan, N. & Reese, W. H. (Eds.) *Life-span developmental psychology: Dialectical perspectives on experimental research*, pp. 135-158. New York, US: Academic Press.

Ghali, S., Fisher, H. L., Joyce, J., Major, B., Hobbs, L., Soni, S., ... & Johnson, S. (2013). Ethnic variations in pathways into early intervention services for psychosis. *The British Journal of Psychiatry*, *202*(4), 277-283.

Glaser, B. G. & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, US: Aldine.

Grealish, A., Tai, S., Hunter, A. and Morrison, A.P. (2013). Qualitative Exploration of Empowerment from the Perspective of Young People with Psychosis. *Clinical Psychology and Psychotherapy, 20*, 136-148.

Habib, N., Dawood, S., Kingdon, D., & Naeem, F. (2015). Preliminary evaluation of culturally adapted CBT for psychosis (CA-CBTp): findings from developing culturally-sensitive CBT project (DCCP). *Behavioural and Cognitive Psychotherapy*, *43*(2), 200-208.

Häfner, H., Löffler, W., Maurer, K., Hambrecht, M., & Heiden, W. A. D. (1999). Depression, negative symptoms, social stagnation and social decline in the early course of schizophrenia. *Acta Psychiatrica Scandinavica*, *100*(2), 105-118.

Hansen, H., Stige, S. H., Davidson, L., Moltu, C., & Veseth, M. (2018). How do people experience early intervention services for psychosis? A meta-synthesis. *Qualitative Health Research*, *28*(2), 259-272.

Harrison, G., Hopper, K. I. M., Craig, T., Laska, E., Siegel, C., Wanderling, J. O. E., ... & Holmberg, S. K. (2001). Recovery from psychotic illness: a 15-and 25-year international follow-up study. *The British Journal of Psychiatry*, *178*(6), 506-517.

Hart, A. & Waddingham, A. (2018). *The mental health act: An alternative review*. *Hearing Voices Network.* Retrieved from: https://www.hearing-voices.org/wp-content/uploads/2018/12/HVN-Alternative-MH-Act-Review_web.pdf. Accessed 14th April 2021.

Health and Wellbeing Profile (2020) Retrieved from: https://jsna.bradford.gov.uk/documents/Community%20Partnership%20and%20area

%20profiles/02%20Community%20Partnerships%20Adult%20Health%20Profiles/Sout
h%2010%20Community%20Partnership%20-%202020.pdf. Accessed 22nd April 2020.

Helman, C. (2007). *Culture, health and illness*. CRC press.

Hendy, C., & Pearson, M. (2020). Peer supported open dialogue in a UK NHS trust–a qualitative exploration of clients' and network members' experiences. *The Journal of Mental Health Training, Education and Practice*, 15(2), 95-103.

Henrich, J., Heine, S. J., & Norenzayan, A. (2010). The weirdest people in the world?. *The Behavioral and Brain Sciences*, *33*(2-3), 61–135.

Henriksen, M. G., & Parnas, J. (2014). Self-disorders and schizophrenia: a phenomenological reappraisal of poor insight and noncompliance. *Schizophrenia Bulletin*, *40*(3), 542-547.

Hernández-Wolfe, P. (2011). Decolonization and "Mental" Health: A Mestiza's Journey in the Borderlands. *Women & Therapy*, *34*(3), 293-306.

Hickling, F., McKenzie, K., Mullen, R., & Murray, R. (1999). A Jamaican psychiatrist evaluates diagnoses at a London psychiatric hospital. *British Journal of Psychiatry, 175*(3), 283-285.

Higgins, R. L., & Leibowitz, R. Q. (2002). Reality negotiation. In Snyder, R. C. & Lopez, J. S. (Eds.), *Handbook of Positive Psychology*, pp. 351-365. New York, US: Oxford University Press.

Hopper, K., & Wanderling, J. (2000). Revisiting the developed versus developing country distinction in course and outcome in schizophrenia: results from ISoS, the WHO collaborative followup project. *Schizophrenia Bulletin*, *26*(4), 835-846.

Hossain, M. M., Purohit, N., Sultana, A., Ma, P., McKyer, E. L. J., & Ahmed, H. U. (2020). Prevalence of mental disorders in South Asia: an umbrella review of systematic reviews and meta-analyses. *Asian Journal of Psychiatry*, 51, 102041.

Husserl, E. (1927). Phenomenology. *Journal of the British Society for Phenomenology, 2*, 77-90.

Hwang, W. C., Myers, H. F., Abe-Kim, J., & Ting, J. Y. (2008). A conceptual paradigm for understanding culture's impact on mental health: The cultural influences on mental health (CIMH) model. *Clinical Psychology Review*, *28*(2), 211-227.

Ichinose, H., Nakane, Y., Nakane, H., Kinoshita, H., Ohta, Y., Honda, S., & Ozawa, H. (2010). Nagasaki Schizophrenia Study: relationship between ultralong-term outcome (after 28 years) and duration of untreated psychosis. *Acta Medica Nagasakiensia, 54*(3), 59-66.

Immigration from the Commonwealth White paper [CMND 2739]. 1965 (United Kingdom). Retrieved from: https://api.parliament.uk/historic-hansard/lords/1965/aug/02/immigration-from-the-commonwealth. Accessed 19th April 2021.

Islam Z., Rabiee F., & Singh, S.P. (2015) Black and Minority Ethnic Groups' Perception and Experience of Early Intervention in Psychosis Services in the United Kingdom. *Journal of Cross-Cultural Psychology, 46*(5), 737–753.

Iyer, S. N., Mangala, R., Thara, R., & Malla, A. K. (2010). Preliminary findings from a study of first-episode psychosis in Montreal, Canada and Chennai, India: comparison of outcomes. *Schizophrenia Research*, *121*(1-3), 227–233.

Jongsma, H. E., Turner, C., Kirkbride, J. B., & Jones, P. B. (2019). International incidence of psychotic disorders: a systematic review and meta-analysis. *The Lancet Public Health, 4*(5), e229-e244.

Johnson, S., Sathyaseelan, M., Charles, H., Jeyaseelan, V., & Jacob, K. S. (2012). Insight, psychopathology, explanatory models and outcome of schizophrenia in India: a prospective 5-year cohort study. *BMC Psychiatry*, *12*(1), 1-12.

Johnstone, L., & Boyle, M. (2018). The Power Threat Meaning Framework: An Alternative Nondiagnostic Conceptual System. *Journal of Humanistic Psychology*, *00*(0), 1-18.

Justice, L., Brems, C., & Ehlers, K. (2018). Bridging body and mind: Considerations for trauma-informed yoga. *International Journal of Yoga Therapy*, *28*(1), 39-50.

Kapadia, D., Nazroo,J., & Tranmer, M. (2018). Ethnic differences in women's use of mental health services: do social networks play a role? Findings from a national survey. *Ethnicity and Health*, *23*(3), 293-306.

Kesby, J. P., Eyles, D. W., McGrath, J. J., & Scott, J. G. (2018). Dopamine, psychosis and schizophrenia: the widening gap between basic and clinical neuroscience. *Translational Psychiatry, 8*(1), 30-30.

Kirkbride, J. B., Fearon, P., Morgan, C., Dazzan, P., Morgan, K., Tarrant, J., ... & Mallett, R. M. (2006). Heterogeneity in incidence rates of schizophrenia and other psychotic syndromes: findings from the 3-center AeSOP study. *Archives of General Psychiatry*, *63*(3), 250-258.

Kirkbride, J. B., Errazuriz, A., Croudace, T. J., Morgan, C., Jackson, D., Boydell, J., . . . Jones, P. B. (2012). Incidence of schizophrenia and other psychoses in England, 1950–2009: a systematic review and meta-analyses. *PloS one, 7*(3), e31660.

Kirkbride, J. B., Hameed, Y., Ioannidis, K., Ankireddypalli, G., Crane, C. M., Nasir, M., . . . Jones, P. B. (2017). Ethnic Minority Status, Age-at-Immigration and Psychosis Risk in Rural Environments: Evidence From the SEPEA Study. *Schizophrenia Bulletin, 43*(6), 1251-1261.

Kirmayer, L. J. & Bhugra D. (2009). Culture and mental illness: social context and explanatory models. In Salloum, I. M., & Mezzich, J. E. (Eds.) *Psychiatric diagnosis: Patterns and prospects*. New York, US: Wiley.

Kleinman, A. (1980). *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry* (Vol. 3). California, US: University of California Press.

Kline, E., & Thomas, L. (2018). Cultural factors in first episode psychosis treatment engagement. *Schizophrenia Research*, *195*, 74-75.

Knight, M. T., Wykes, T., & Hayward, P. (2003). 'People don't understand': An investigation of stigma in schizophrenia using Interpretative Phenomenological Analysis (IPA). *Journal of Mental Health*, *12*(3), 209-222.

Lally, J., Ajnakina, O., Stubbs, B., Cullinane, M., Murphy, K. C., Gaughran, F., & Murray, R. M. (2017). Remission and recovery from first-episode psychosis in adults: systematic review and meta-analysis of long-term outcome studies. *The British Journal of Psychiatry*, *211*(6), 350-358.

Langa, M. E., & Gone, J. P. (2020). Cultural Context in DSM Diagnosis: An American Indian Case Illustration of Contradictory Trends. *Transcultural Psychiatry*, *57*(4), 567–580.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102-120.

Lebowitz, M. S., & Ahn, W. K. (2014). Effects of biological explanations for mental disorders on clinicians' empathy. *Proceedings of the National Academy of Sciences*, *111*(50), 17786-17790.

Leonhardt, B. L., Hamm, J. A., & Lysaker, P. H. (2020). The recovery model and psychosis. In *A Clinical Introduction to Psychosis: Foundations for Clinical Psychologists and Neuropsychologists,* pp. 113-132. Indianapolis, US: Academic Press.

Levit, J., Valderrama, J., Georgakopoulos, P., AA-GPC Brooklyn, Pato, C. N., & Pato, M. T. (2021). Childhood Trauma and Psychotic Symptomatology in Ethnic Minorities With Schizophrenia. *Schizophrenia Bulletin Open*, *2*(1), sgaa068.

Lobban, F., Barrowclough, C., & Jones, S. (2004). The impact of beliefs about mental health problems and coping on outcome in schizophrenia. *Psychological Medicine, 34*(7), 1165-1176.

Loganathan, S., & Murthy, R. S. (2011). Living with schizophrenia in India: gender perspectives. *Transcultural Psychiatry*, *48*(5), 569-584.

Longden, E., Sampson, M., & Read, J. (2016). Childhood adversity and psychosis: generalised or specific effects?. *Epidemiology and Psychiatric Sciences*, *25*(4), 349-359.

Lucero, E. (2011). From tradition to evidence: Decolonization of the evidence-based practice system. *Journal of Psychoactive Drugs*, *43*(4), 319-324.

Luhrmann, T. M., Padmavati, R., Tharoor, H., & Osei, A. (2015). Differences in voice-hearing experiences of people with psychosis in the U.S.A., India and Ghana: interview-based study. *The British Journal of Psychiatry*, *206*(1), 41–44.

Loewenthal, M. K. & Lewis, A. C. (2011). Mental health, religion and culture. *The Psychologist, 24*, 259-259.

Lyons, E. & Coyle, A. (2016). *Analysing Qualitative Data in Psychology.* London, UK: Sage Publications.

Lysaker, P. H., Kukla, M., Vohs, J. L., Schnakenberg Martin, A. M., Buck, K. D., & Hasson Ohayon, I. (2019). Metacognition and recovery in schizophrenia: from research to the development of metacognitive reflection and insight therapy. *Journal of Experimental Psychopathology*, *10*(1), 331-341.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, *91*(1), 1-20.

Mann, F., Fisher, H. L., Major, B., Lawrence, J., Tapfumaneyi, A., Joyce, J., ... & Johnson, S. (2014). Ethnic variations in compulsory detention and hospital admission for psychosis across four UK Early Intervention Services. *BMC Psychiatry*, *14*(1), 1-12.

Major, B., & O'Brien, L. T. (2005). The social psychology of stigma. *Annual Review of Psychology*, 56, 393-421.

Marshall, M., Lewis, S., Lockwood, A., Drake, R., Jones, P., & Croudace, T. (2005). Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: a systematic review. *Archives of General Psychiatry, 62*(9), 975-983.

Mawson, A., Berry, K., Murray, C., & Hayward, M. (2011). Voice hearing within the context of hearers' social worlds: An interpretative phenomenological analysis. *Psychology and Psychotherapy: Theory, Research and Practice*, *84*(3), 256-272.

McCabe, R., & Priebe, S. (2004). Explanatory models of illness in schizophrenia: comparison of four ethnic groups. *The British Journal of Psychiatry, 185*(1), 25-30.

McCarthy-Jones, S., Marriott, M., Knowles, R., Rowse, G., & Thompson, A. R. (2013). What is psychosis? A meta-synthesis of inductive qualitative studies exploring the experience of psychosis. *Psychosis*, *5*(1), 1-16.

McDonald, K., Ding, T., Ker, H., Dliwayo, T., Osborn, D., Wohland, P., . . . Kirkbride, J. (2021). Using epidemiological evidence to forecast population need for early treatment programmes in mental health: A generalisable Bayesian prediction methodology applied to and validated for first-episode psychosis in England. *The British Journal of Psychiatry*, 219(1), 383-391.

McManus, S., Bebbington, P., Jenkins, R., & Brugha, T. (eds.) (2016) *Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014*. Leeds, UK: NHS Digital.

Mental Wellbeing in Profile (2016-2021). Retrieved from: https://www.bradford.gov.uk/media/3578/mental-wellbeing-strategy-in-bradford-district-craven.pdf. Accessed 22nd April 2021.

Mental Health Research Network (MHRN) (2010). *MHRN Service Users and Carers Payments Policy*. Retrieved from: https://cdn.ymaws.com/www.tmn.ac.uk/resource/collection/D80ACB4B-2D30-4A0C-919A-2A01461D3AD7/Model_payment_policy_for_MHRN_Hubs[1].pdf. Accessed 3rd August 2020.

Mir, G., Meer, S., Cottrell, D., McMillan, D., House, A., & Kanter, J. W. (2015). Adapted behavioural activation for the treatment of depression in Muslims. *Journal of Affective Disorders*, *180*, 190-199.

Mirza, A., Birtel, M. D., Pyle, M., & Morrison, A. P. (2019). Cultural differences in psychosis: The role of causal beliefs and stigma in White British and South Asians. *Journal of Cross-Cultural Psychology*, *50*(3), 441-459.

Monteiro, V., Santos, J. Q. d., & Martin, D. (2006). Patients' relatives delayed help seeking after a first psychotic episode. *Brazilian Journal of Psychiatry, 28*(2), 104-110.

Morgan, C., Mallett, R., Hutchinson, G., Bagalkote, H., Morgan, K., Fearon, P., . . . Leff, J. (2005). Pathways to care and ethnicity. 2: Source of referral and help-seeking. Report from the AESOP study. *British Journal of Psychiatry, 186*, 290-296.

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative Health Research*, *25*(9), 1212-1222.

Mostolamsky, T. & Rota, A. (2020). Emic and Etic. In Stein, S. F., Lazar, M., Candea, H., Diemberger, J., Robbins, A., Stasch, R. (Eds.) *The Cambridge Encyclopedia of Anthropology*. Retrieved from: https://www.anthroencyclopedia.com/printpdf/1181. Accessed 6th February 2021.

Naeem, F., Saeed, S., Irfan, M., Kiran, T., Mehmood, N., Gul, M., ... & Kingdon, D. (2015). Brief culturally adapted CBT for psychosis (CaCBTp): a randomized controlled trial from a low income country. *Schizophrenia Research*, *164*(1-3), 143-148.

Naeem, F., Habib, N., Gul, M., Khalid, M., Saeed, S., Farooq, S., & Kingdon, D. (2016a). A qualitative study to explore patients', carers' and health professionals' views to culturally adapt CBT for psychosis (CBTp) in Pakistan. *Behavioural and Cognitive Psychotherapy*, *44*(1), 43-55.

Naeem, F., Khoury, B., Munshi, T., Ayub, M., Lecomte, T., Kingdon, D., & Farooq, S. (2016b). Brief cognitive behavioral therapy for psychosis (CBTp) for schizophrenia: Literature review and meta-analysis. *International Journal of Cognitive Therapy*, *9*(1), 73-86.

Neale, A., & Kinnair, D. (2017). Early intervention in psychosis services. *British Journal of General Practice*, 67(661), 370-371.

Newbigging, K., & Ridley, J. (2018). Epistemic struggles: The role of advocacy in promoting epistemic justice and rights in mental health. *Social Science & Medicine*, *219*, 36-44.

NHS Digital (2017). *Health Survey for England.* London, UK.

NICE (2014). *Psychosis and schizophrenia in adults: treatment and management*. Retrieved from: http://www.nice.org.uk/CG178. Accessed 2nd September 2019. Accessed 3rd April 2020.

Nordgaard, J., Nilsson, L. S., Gulstad, K., & Buch-Pedersen, M. (2021). The Paradox of Help-Seeking Behaviour in Psychosis. *The Psychiatric Quarterly*, *92*(2), 549–559.

Oduola, S., Craig, T., Das-Munshi, J., Bourque, F., Gayer-Anderson, C., & Morgan, C. (2019). Compulsory admission at first presentation to services for psychosis: does ethnicity still matter? Findings from two population-based studies of first episode psychosis. *Social Psychiatry and Psychiatric Epidemiology*, *54*(7), 871–881.

Oduola, S., Craig, T. K., & Morgan, C. (2020). Ethnic variations in duration of untreated psychosis: report from the CRIS-FEP study. *Social Psychiatry and Psychiatric Epidemiology*, 1-11.

Office of National Statistics (2011) *Census: Small population tables for England and Wales*. London, UK: Office for National Statistics.

Olson, M., Seikkula, J., & Ziedonis, D. (2014). The key elements of dialogic practice in open dialogue: Fidelity criteria. Retrieved from: http://www.do-ge.ch/uploads/1/3/9/9/13993272/keyelementsv1.109022014.pdf. Accessed 3rd December 2020.

Okazaki, S., & Sue, S. (1995). Methodological issues in assessment research with ethnic minorities. *Psychological Assessment*, *7*(3), 367-375.

Pai, S., Li, P., Killinger, B., Marshall, L., Jia, P., Liao, J., . . . Labrie, V. (2019). Differential methylation of enhancer at IGF2 is associated with abnormal dopamine synthesis in major psychosis. *Nature Communications, 10*(1), 2046.

Parnas, J. (2015). Differential diagnosis and current polythetic classification. *World Psychiatry*, *14*(3), 284.

Patel, V., Gwanzura, F., Simunyu, E., Lloyd, K., & Mann, A. (1995). The phenomenology and explanatory models of common mental disorder: a study in primary care in Harare, Zimbabwe. *Psychological Medicine, 25*(6), 1191-1199.

Paulik, G. (2012). The role of social schema in the experience of auditory hallucinations: a systematic review and a proposal for the inclusion of social schema in a cognitive behavioural model of voice hearing. *Clinical Psychology & Psychotherapy*, *19*(6), 459-472.

Petrie, K. J., Broadbent, E., & Kydd, R. (2008). Illness perceptions in mental health: Issues and potential applications. *Journal of Mental Health, 17*(6), 559-564.

Penny, E., Newton, E., & Larkin, M. (2009). Whispering on the Water: British Pakistani Families' Experiences of Support From an Early Intervention Service for First-Episode Psychosis. *Journal of Cross-Cultural Psychology*, *40*(6), 969–987.

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, *20*(1), 7-14.

Pinto, R., Ashworth, M., & Jones, R. (2008). Schizophrenia in black Caribbeans living in the UK: an exploration of underlying causes of the high incidence rate. *British Journal of General Practice*, *58*(551), 429-434.

Prajapati, R., & Liebling, H. (2021). Accessing Mental Health Services: a Systematic Review and Meta-ethnography of the Experiences of South Asian Service Users in the UK. *Journal of Racial and Ethnic Health Ddisparities*, 10.1007/s40615-021-00993-x.

Puschner, B., Repper, J., Mahlke, C., Nixdorf, R., Basangwa, D., Nakku, J., Ryan, G., Baillie, D., Shamba, D., Ramesh, M., Moran, G., Lachmann, M., Kalha, J., Pathare, S., Müller-Stierlin, A., & Slade, M. (2019). Using Peer Support in Developing Empowering Mental Health Services (UPSIDES): Background, Rationale and Methodology. *Annals of Global Health*, *85*(1), 1-10.

Putnam, L. (2019). A License to Be Crazy. *Journal of Humanistic Psychology*, *59*(5), 706–713.

Quay, T. A., Frimer, L., Janssen, P. A., & Lamers, Y. (2017). Barriers and facilitators to recruitment of South Asians to health research: a scoping review. *BMJ open*, *7*(5), e014889.

Quellet-Plamondon, C., Rousseau, C., Nicole, L., & Abdel-Baki, A. (2015). Engaging immigrants in early psychosis treatment: a clinical challenge. *Psychiatric Services*, *66*(7), 757-759.

Rácz, J., Kaló, Z., Kassai, S., Kiss, M., & Pintér, J. N. (2017). The experience of voice hearing and the role of self-help group: An interpretative phenomenological analysis. *International Journal of Social Psychiatry*, *63*(4), 307–313.

Ran, M.-S., Weng, X., Chan, C. L.-W., Chen, E. Y.-H., Tang, C.-P., Lin, F.-R., . . . Xiang, M.-Z. (2015). Different outcomes of never-treated and treated patients with schizophrenia: 14-year follow-up study in rural China. *The British journal of psychiatry, 207*(6), 495-500.

Rathod, S., Kingdon, D., Phiri, P., & Gobbi, M. (2010). Developing culturally sensitive cognitive behaviour therapy for psychosis for ethnic minority patients by exploration and incorporation of service users' and health professionals' views and pinions. *Behavioural and Cognitive Psychotherapy*, *38*(5), 511.

Razzaque, R., & Wood, L. (2015). Open dialogue and its relevance to the NHS: opinions of NHS staff and service users. *Community Mental Health Journal*, *51*(8), 931-938.

Razzaque, R., & Stockmann, T. (2016). An introduction to peer-supported open dialogue in mental healthcare. *BJPsych Advances*, *22*(5), 348-356.

Read, J., Bentall, R. P., & Fosse, R. (2009). Time to abandon the bio-bio-bio model of psychosis: Exploring the epigenetic and psychological mechanisms by which adverse life events lead to psychotic symptoms. *Epidemiology and Psychiatric Sciences*, *18*(4), 299-310.

Reed, G. M., First, M. B., Kogan, C. S., Hyman, S. E., Gureje, O., Gaebel, W., ... & Saxena, S. (2019). Innovations and changes in the ICD-11 classification of mental, behavioural and neurodevelopmental disorders. *World Psychiatry*, *18*(1), 3-19.

Rienzo C. & Vargas-Silva C. (2020) *Migrants in the UK: an overview. Migration Observatory briefing*. Retrieved from: https://migrationobservatory.ox.ac.uk/wp-content/uploads/ 2017/02/Briefing-Migrants-in-the-UK-An-Overview.pdf. Accessed 13th March 2021.

Ritsher, J. B., Lucksted, A., Otilingam, P. G., & Grajales, M. (2004). Hearing voices: Explanations and implications. *Psychiatric Rehabilitation Journal*, *27*(3), 219.

Romme, M. A., & Escher, A. D. (1989). Hearing voices. *Schizophrenia Bulletin*, *15*(2), 209-216.

Roper-Hall, A. (1998) Working systemically with older people and their families who have 'come to grief'. In Sutcliff, P., Tufnell, G & Cornish, U. (Eds) *Working with the Dying and Bereaved: Systemic Approaches to Therapeutic Work*. London, UK: Macmillan.

Roper-Hall, A. (2008) Systemic interventions and older people. In Woods, R. & Clare, L. (Eds) *Handbook of the Clinical Psychology of Ageing (2nd Edition).* London, UK: Wiley.

Rothman, A., & Coyle, A. (2018). Toward a framework for Islamic psychology and psychotherapy: An Islamic model of the soul. *Journal of religion and health*, *57*(5), 1731-1744.

Saleem, M. Brewin, A., Ding, C., Nazar, Q., Robinson, J., Hosalli, P., Nazari, J., Garnham, M., Inglehearn, F. C., Cardno, G. A., & Mahmood, T. (2019). Risk of psychosis in Yorkshire South Asians. *Journal of Psychiatric Intensive Care, 15*(2), 117-121.

Salway, S., Mir, G., Turner, D., Ellison, G. T., Carter, L., & Gerrish, K. (2016). Obstacles to "race equality" in the English National Health Service: Insights from the healthcare commissioning arena. *Social Science & Medicine*, *152*, 102–110.

Sam, D. L., & Berry, J. W. (2010). Acculturation: When Individuals and Groups of Different Cultural Backgrounds Meet. *Perspectives on Psychological Science*, *5*(4), 472–481.

Sar, V., Taycan, O., Bolat, N., Özmen, M., Duran, A., Öztürk, E., & Ertem-Vehid, H. (2010). Childhood trauma and dissociation in schizophrenia. *Psychopathology*, *43*(1), 33-40.

Saravanan, B., Jacob, K. S., Deepak, M. G., Prince, M., David, A. S., & Bhugra, D. (2008). Perceptions about psychosis and psychiatric services: a qualitative study from Vellore, India. *Social Psychiatry and Psychiatric Epidemiology*, *43*(3), 231-238.

Sass, L. A., & Parnas, J. (2003). Schizophrenia, consciousness, and the self. *Schizophrenia Bulletin*, *29*(3), 427–444.

Schafer, I., & Fisher, H. L. (2011). Childhood trauma and psychosis - what is the evidence? *Dialogues in Clinical Neuroscience, 13*(3), 360-365.

Seikkula, J., Birgitta, A., Aaltonen, J. (2001). Open dialogue in psychosis I: An introduction and case illustration. *Journal of Constructivist Psychology*, *14*(4), 247-265.

Shah, I., Khalily, M,T., Ahmad, I., Hallahan, B. (2019) Impact of Conventional Beliefs and Social Stigma on Attitude Towards Access to Mental Health Services in Pakistan. *Community Mental Health Journal, 55*(3), 527-533.

Sheik, A., & Gatrad, R. A., (2007) *Caring for Muslim patients.* (2nd Edition). UK: Radcliffe Medical Press.

Singh, S. P., Brown, L., Winsper, C., Gajwani, R., Islam, Z., Jasani, R., ... & Birchwood, M. (2015). Ethnicity and pathways to care during first episode psychosis: the role of cultural illness attributions. *BMC Psychiatry*, *15*(1), 1-8.

Skinner, R. (2019). Traditions, paradigms and basic concepts in Islamic psychology. *Journal of Religion and Health*, *58*(4), 1087-1094.

Smith, B. (2004). Beyond concepts: Ontology as reality representation. In Achille C. Varzi & Laure Vieu (Eds.), *Formal Ontology in Information Systems (FOIS)*, 1-12. Retrieved from: https://philpapers.org/archive/SMIBCO.pdf. Accessed 19th May 2021.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health, 11,*261–271.

Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology and Health*, *22*(5), 517-534.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. UK: Sage Publications.

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9-27.

Srinivasan T. N., Rangaswamy, T., & Raman, P. (2004). Duration of untreated psychosis and treatment outcome in schizophrenia patients untreated for many years. *Australian & New Zealand Journal of Psychiatry, 38*(5), 339-343.

Sternthal, M. J., Slopen, N., & Williams, D. R. (2011). Racial Disparities in Health: How Much Does Stress Really Matter? *Du Bois Review: Social Science Research on Race, 8*(1), 95-113.

Suhail, K., & Cochrane, R. (2002). Effect of culture and environment on the phenomenology of delusions and hallucinations. *International Journal of Social Psychiatry*, *48*(2), 126-138.

Tackling Health Inequalities for BAME Communities and Colleagues. (2020). Retrieved from: https://www.yhahsn.org.uk/news/tackling-health-inequalities-for-bame-communities-and-colleagues/. Accessed 22nd April 2021.

Tahira, A., & Agius, M. (2012). Epigenetics and migration - considerations based on the incidence of psychosis in South Asians in Luton, England. *Psychiatria Danubina*, 24(1), 194–196.

Thirthalli, J., Channaveerachari, N. K., Subbakrishna, D. K., Cottler, L. B., Varghese, M., & Gangadhar, B. N. (2011). Prospective study of duration of untreated psychosis and outcome of never-treated patients with schizophrenia in India. *Indian Journal of Psychiatry, 53*(4), 319.

Time to change. (2010). *Family matters: a report into attitudes towards mental health problems in the South Asian community in Harrow, North West London.* Retrieved

from: https://www.bl.uk/collection-items/family-matters-a-report-into-attitudes-towards-mental-health-problems-in-the-south-asian-community-in-harrow-north-west-london# Accessed on 14th May 2021.

Tindal, C. (1994). Report Writing. In Banister, P., Burman, E., Parker, I., Taylor, M., & Tindall, C. (Eds.) *Qualitative methods in psychology: A research guide.* UK: Open University Press.

Tirupati, S. & Thara, R. (2001). Beliefs about causation of schizophrenia: Do Indian families believe in supernatural causes?. *Social Psychiatry and Psychiatric Epidemiology, 36*(3), 134-140.

Todd, D., Simpson, J., & Murray, C. (2010). An interpretative phenomenological analysis of delusions in people with Parkinson's disease. *Disability and rehabilitation*, *32*(15), 1291-1299.

Tuffour, I. (2017). A critical overview of interpretative phenomenological analysis: A contemporary qualitative research approach. *Journal of Healthcare Communications*, *2*(4), 52.

Vagle, M. D., Hughes, H. E., & Durbin, D. J. (2009). Remaining Skeptical: Bridling for and with One Another. *Field Methods*, *21*(4), 347–367.

Varese, F., Smeets, F., Drukker, M., Lieverse, R., Lataster, T., Viechtbauer, W., ... & Bentall, R. P. (2012). Childhood adversities increase the risk of psychosis: a meta-analysis of patient-control, prospective-and cross-sectional cohort studies. *Schizophrenia Bulletin*, *38*(4), 661-671.

Valle, R. (2020). Schizophrenia in ICD-11: Comparison of ICD-10 and DSM-5. *Revista de Psiquiatrìa y Salud Mental, 13*(2), 95-104.

Virdee, G., Frederick, T., Tarasoff, L. A., McKenzie, K., Davidson, L., & Kidd, S. A. (2017). Community participation within the context of recovery: Multiple perspectives on South Asians with schizophrenia. *International Journal of Culture and Mental Health*, *10*(2), 150-163.

Waheed, W., Mirza, N., Waheed, M. W., Blakemore, A., Kenning, C., Masood, Y., ... & Bower, P. (2020). Recruitment and methodological issues in conducting dementia research in British ethnic minorities: A qualitative systematic review. *International Journal of Methods in Psychiatric Research*, *29*(1), e1806.

Weatherhead, S., & Daiches, A. (2010). Muslim views on mental health and psychotherapy. *Psychology and Psychotherapy: Theory, Research and Practice, 83*(1), 75-89.

Willig, C., & Rogers, W. S. (2017). *The SAGE handbook of qualitative research in psychology*. London, UK: Sage Publications.

Wilkinson, R., & Pickett, K. (2010). *The spirit level. Why equality is better for everyone*. UK: Penguin.

World Health Organization. (2016). *International classification of diseases for mortality and morbidity statistics* (10th Revision). Retrieved from: https://icd.who.int/browse10/2016/en. Accessed 7th January 2020.

World Health Organization. (2019). *International classification of diseases for mortality and morbidity statistics* (11th Revision). Retrieved from: https://icd.who.int/en. Accessed 30th April 2021.

Yardley, L. (2000) Dilemmas in qualitative health research. *Psychology and Health,* 15(2), 215-228.

Zubin, J., & Spring, B. (1977). Vulnerability: A new view of schizophrenia. *Journal of Abnormal Psychology, 86*(2), 103-126.

- Appendix -

Appendix I: Semi-structured topic guide

Note to ethics: This interview schedule is semi-structured and serves as a guide only. The aim is for me to have some core questions of interest, but to be flexible and allow the participant to explore and share their own experiences and relevant topics. Therefore, the content and format of this interview is subject to changes throughout the research.

Semi-structured topic guide

Introduction:
- Introduce self. Check if good time, private location.
- Go through information sheet and provide the space for questions or concerns.
- Explain that I will be asking them some questions about their experience of psychosis[1] and how they have made sense of these experiences over time.
- Explain that the interview will be flexible and they should share things that they feel are relevant to the interview.
- Explain that some questions are personal but they are free to share as little or as much as they would like and they are free to skip questions if they feel uncomfortable.
- Explain the consent process and obtain informed consent.
- Start recording.

Introductory question: what interested you to take part in this project?

1. I'm interested to hear about your first experience of noticing something out of the ordinary, maybe feeling different or something unusual happening. Can you tell me about it…
   a. (prompt, how did you come to be involved with EI? Can you tell me more about these experiences?)
   b. Where were you?
   c. What was around you? (inc other people)
   d. What other things were happening around that time? (stress, cannabis?)

2. Could you tell me more about what happened afterwards?
   a. What did you think was happening?
   b. How did you feel at the time? How was this experience for you?
   c. Did you notice any changes before this, for example in your mood or thinking?
   d. What did you think these meant?
   e. What did you do?

3. Did you share this with anyone? Family or friends…

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[1] Participants will be asked about the language they prefer to use to describe their experiences and this will be used throughout the interview.

      a. What had they noticed?
      b. How did they react?
      c. What did they think was happening? What did you think about that?
      d. How did that make you feel?

4. As you know I'm interested in how your ethnicity (being south Asian), culture (/religion) or upbringing might have impacted your experience with [psychosis]. Can you tell me how you think it has impacted the experience you described just now?
      a. How did your family react? Did they agree with your views or hold different views?
      b. How that felt, what you thought? Have relationships changed?
      c. How did your community (extended family, family relations, neighbours) react? *beliefs about SA people, being a minority
      d. What about work/uni or your social life (friendships etc)?

5. How do you think being South Asian, or another part of your identity [use their examples] has affected your experiences?
      a. How? If not why?
      b. How has this impacted your role/position in the family? How have family members/ others interacted with you?
      c. Have there been any changes in how the community sees you? What might they be?

6. Are there any (psychotic) experiences that you can think of that really stand out?
      a. Can you describe that happened?
      b. How were you feeling?
      c. What were you thinking?

7. Now you've told me about your different experiences what did you think was happening?
      a. What did you believe was happening?
      b. Why do you think you had these experiences?
      c. What was it like to have these experiences?
      d. What did these experiences mean to you?
      e. How did they make you feel?

8. Could you tell me about the experience(s) that led you to seeking help?
      a. How long did you have these experiences before this one?
      b. What do you think stopped you from seeking help before this?
      c. Where did you seek help? (Spiritual/religious/medical treatment)
      d. How was that experience for you?
      e. Did you think you needed to see a X/doctor?
      f. How did you feel about seeing a X/doctor?
      g. How did your family react to this, were they involved? Do you think they were okay with you seeing help about these experiences?

9. Could you tell me more about how you've found being with the service?
   a. Tell me about the types of conversations you had about your experiences? Were there times you didn't feel understood? Did that fit with what you believed?
   b. How did it feel to share your experience with them?

10. Can you tell me about a recent experience?
   a. How have things changed over time?
   b. What are they like now?
   c. Has anything about your beliefs about your experiences changed?
      i. In what way?
      ii. Can you think of why they have changed?
   d. What helped you with these experiences?
   e. What has been unhelpful?
   f. What do you think about these experiences now?
   g. How has your family been?
   h. How has it affected your relationships with others?

11. Is there anything else you would like to share with me about your experience with psychosis that I have not asked you about?

Ending the interview:
   • Check whether there is anything else they want to share/anything that has not been covered.
   • Ask how they have found the interview and whether there is anything that they shared that they would like omitted from the analysis.
   • Check for any distress and follow the necessary procedures as agreed by the team/key worker.
   • Explain how the results will be disseminated.
   • Obtain consent for additional information to be taken from participant or staff.

Obtain additional information from participant or staff:
   1. Age
   2. Ethnicity
   3. Year of first contact with mental health services
   4. Length of admission to early intervention services
   5. Current/ most recent diagnosis
   6. Country(s) of birth of service user and parents/carers

Prompts for the questions:
   • tell me more about x?
   • could you give me a bit more detail about that?
   • I'd be interested to hear more about that…?

Notes about my initial response to the interview:
- My reactions/feelings/emotions to the participant and their experiences.
- Any observations noticed from the interview, e.g. non-verbal cues, silences and long pauses.
- Questions that I should have asked (which could be included in the next interview) .
- Questions/prompts which were perhaps unhelpful and may be omitted from the next interview.

If face-to-face or video:

Appearance – tidy, clean or dishevelled; any unusual/odd clothing, adornments…
Behaviour – calm or agitated, little movement or overactive, anything odd/eccentric/bizarre, seemed to be listening/seeing things you couldn't…
Speech – normal amount, rate, coherence, or limited speech, or evidence of formal thought disorder – disjointed, vague, incoherent speech.
Mood/affect – normal, restricted, depressed, anxious/agitated, elated, irritable…
Attention – engaged, distracted…

Appendix II: Staff Information Sheet

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Staff Information Sheet

An exploration of the experience and understanding of psychosis in a South Asian population: An Interpretive Phenomenological Analysis.

My name is Krisna Patel. I am in my second year of training to be a Clinical Psychologist at the University of Leeds. As part of my course I am completing a research study which is being supervised by Dr Alistair Cardno, Dr Tom Isherwood and Dr Anita Brewin. I am wondering if you might be interested in helping with the study which I have described below. Thank you for taking the time to read the information.

Aims of the study

Research suggests that those from Black and Asian Minority Ethnic (BAME) groups have different experiences, pathways into care and typically have a longer duration of untreated psychosis. There is currently limited research into how people from BAME backgrounds experience and make sense of psychosis. This is particularly so in those from a South Asian ethnic minority group, despite this group being the second largest in the U.K. As you know, providing a culturally informed service to every individual who experiences psychosis is vital.

This study is intended to provide people from a South Asian background with the opportunity to share their personal and individual experiences of psychosis and how they have made sense of it. This is a qualitative study in which I will interview participants about these experiences. The hope is that exploring participants' individual accounts will improve our understanding of their experiences and how they have made sense of them, and this will help us provide more culturally informed care for service users in the future.

What will taking part involve?

I would like to interview between six to ten people interested in sharing their experiences of psychosis with me. Participants will be asked about the first time they noticed something was unusual, what is was like and what the participant thought was happening. I will also explore how these experiences have affected the participant (including how they felt/feel about them), what the experiences meant to them and how they have coped.

Each person will be asked to attend two interviews approximately one week apart. Each interview process will be no more than 90 minutes and the participant will be free to take as many breaks as they like or terminate the interview if they become fatigued.

After the first interview, with the participants agreement, I would like to ask them and/or a member of staff to provide me with some brief additional information. This will include:

1. Age
2. Ethnicity
3. Year of first contact with mental health services
4. Length of time with early intervention services
5. Current/ most recent diagnosis
6. Country(s) of birth for service user and parents

Who can take part?

We would be grateful if staff would give the participant information sheet to people who meet the following criteria:

Inclusion criteria

- Have the capacity to give informed consent.
- Experience of having psychosis at some time in their life.
- Are able to engage in an interview about their experience with psychosis.
- South Asian ethnicity, from three broad self-ascribed ethnic groups: Bangladeshi, Indian and Pakistani.
- Ability to converse in English.

Exclusion criteria

- Unable to provide informed consent
- Would be at significant risk of becoming distressed if they took part in the study (as assessed by the staff professionals involved in their care).
- Are currently experiencing features of florid psychosis, that would make it difficult to engage in an interview.
- Under 18 years old.
- Not able to converse in English.

What do I do if a service user would like to take part?

Please provide each participant with a minimum of 48 hours after they have received the participant information sheet before you ask them if they are happy for you to let the researcher know they are interested.

If anyone does express an interest in taking part please email Krisna Patel: umkpa@leeds.ac.uk.

In this email please do not provide the service users name. Please let me know of the date and time that you have agreed with the service user for me to meet them at the EI base where they usually receive their care.

Please let me know if the service user would like to speak on the telephone or using another method such as Skype, FaceTime or WhatsApp in the email and I will liaise with you about this to organise.

During this meeting, if the service user is happy to take part and is free we may conduct the first interview.

Contacts for further information

If you would like further information please contact me or anyone else from the research team:

Email: **umkpa@leeds.ac.uk**   Telephone: **0113 343 2732**

Krisna Patel (Psychologist in Clinical Training)
Clinical Psychology Programme
Leeds Institute of Health Sciences
University of Leeds
Leeds, LS2 9NL

Name: Dr Tom Isherwood
Job title: Admissions Tutor & Deputy Clinical Director

Email address: **t.m.isherwood@leeds.ac.uk**   Telephone: **0113 343 2732**
Leeds Institute of Health Sciences
University of Leeds
1095, Worsley Building
Clarendon Way
Leeds
LS2 9NL

Name: Dr Alastair Cardno
Job title: Senior Lecturer in Psychiatry

Email address: **a.g.cardno@leeds.ac.uk**   Telephone: **0113 343 2732**
Division of Psychological and Social Medicine
Leeds Institute of Health Sciences
Faculty of Medicine and Health
University of Leeds
Level 10, Worsley Building
Leeds LS2 9NL
UK

Name: Dr Anita Brewin
Job title: Consultant Clinical Psychologist, Head of Psychological Therapies in BDCFT

Email address: **anita.brewin@bdct.nhs.uk**   Telephone: **07738977326**

Thank you for spending the time to read and consider this study; any support would be greatly appreciated.

Appendix III: Participant Information Sheet

NHS
Bradford District Care
NHS Foundation Trust

UNIVERSITY OF LEEDS

Participant Information Sheet

An exploration of the experience and understanding of psychosis in a South Asian population: An Interview Study.

My name is Krisna Patel; I am in my second year of training to be a Clinical Psychologist at the University of Leeds. As part of my course I am doing some research; this research aims to find out about people's personal experiences of psychosis and how people have made sense of these experiences. You are being invited to take part in this research. It is completely up to you whether you decide to take part; please feel free to read through this information. Talk to others about the study if you wish.

Thank you for taking the time to read through this information sheet.

What is the purpose of the study?

Some studies have explored what it is like to experience psychosis, however very few studies have invited service users from a South Asian ethnic minority group to talk in detail about their personal experiences of psychosis. This study is about giving you the opportunity to share your own experiences and how you have made sense of them. You might find it helpful to think about things that have happened and share your story; or things that have been difficult or gone really well. By learning about the experience of people who are from different backgrounds we may be able to improve our understanding of service user needs, and improve the service we provide.

Taking part is voluntary and will not affect the care you receive.

Why have I been approached about this study?

A member of staff has given this information sheet to you because you have experiences of psychosis and they think that you may be interested in taking part in this study and sharing some of your own experiences and life story.

Do I have to take part?

No, it is your decision whether you wish to take part in the study. Please feel free to discuss taking part in this study with your family and friends before you decide.

What happens if I decide to take part?

If you are interested in participating, a member of staff from your team will ask whether you agree to me coming to meet with you or talk to you via the telephone, Skype, WhatsApp or FaceTime, depending on what you prefer. They will organise a time that suits you and will let me know.

If we meet in person it will be where you usually meet your care team. This will be either Culture Fusion, Meridian House or Field House in the Bradford.

We can have up to 90 minutes and we will have regular breaks as needed or stop the interview if you no longer want to continue. If we meet in person I am happy to provide light refreshments.

Together we will do the three following things:

1. Discuss what the study involves and I will answer any questions you may have.
2. If you wish to continue, I will ask you to provide consent (either written or verbal), stating that you agree to take part.
3. I will invite you to talk about your experiences of psychosis and how you have made sense of them. This will take no longer than 90 minutes and will be audio recorded. I have a few questions to ask you, but more importantly I hope you will be able to talk to me about whatever feels relevant and comfortable. There are no right or wrong answers - we really want to know about your unique experience.

After our meeting I will ask you or staff to give me some more information that you have consented to. This will include:

1. Age
2. Ethnicity
3. Year of first contact with mental health services
4. Length of time with the early intervention services
5. Current/ most recent diagnosis
6. Country(s) of birth of you and your parents

After we have finished the interview, I will offer you the opportunity to have a second interview a week later. You do not have to take part in this if you do not want to.

What happens if I change my mind or do not want to carry on with the interview?

You can stop being part of the study at any time, without giving a reason, even if you decide to take part initially, but we will keep information about you that we already have. If you decide to withdraw, you will still receive your normal care.

You will have up to one week after the interviews to withdraw the information you've shared. Information you have given will be confidential, which means we will keep the information within the research team. After one week your interview will be transcribed,

which means they will be typed up word for word and anonymised, which means your name will be removed and therefore you will no longer be able to withdraw the information you've given me.

Are there any possible risks or disadvantages of taking part?

Sometimes people find it difficult or uncomfortable to talk about their experiences. However, if there is anything you do not wish to talk about you do not need to. If there is anything you do talk about that you find upsetting you might find it helpful to talk about this with me during the meetings or a member of staff afterwards.

Are there any possible advantages of taking part?

There may not be any immediate or direct benefits to you by taking part. You might find it helpful to talk about your experiences, especially if you have not had much opportunity to share them before. The findings of this research will help us think about how we can better understand the experiences of psychosis of people from different cultural backgrounds. Your contribution will lead to better services for people in the future.

What happens to the information about me?

This study is being sponsored by the University of Leeds. We will need to use information from you for this research project. This information will include your name and may include your contact details (telephone number or email address) if we conduct a telephone or online interview. We will need this information to do this research. 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 number 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.

All personal information will be kept strictly confidential in accordance with the Data Protection Act 2018.

The interview will be audio recorded (on a password protected device) and then it will be transcribed. Transcription is the way we convert the audio recordings (what you say) to text, word for word. The transcriber will agree to maintain strict confidentiality according to University policy. After transcription, the audio recording, will be deleted. Your name on the transcript data will be replaced with a participant number to protect your confidentiality, making it anonymised.

Any personally identifiable information will only be available to members of the research team and be initially stored on a password protected recording device. Your interview transcript will be held securely at the University of Leeds for 3 years, from the completion of the project and then destroyed securely. Quotes from your interview may be used as examples of what people have said but any potentially identifiable information will be removed and your anonymity will be preserved. This information will only be used for the purposes of the current study.

We will keep any information collected from you as a result of this study confidential. However, if during the research we become concerned about any risk to you or others I will need to share this information with your care team to ensure you and other people's safety. Where ever possible, I will discuss this with you beforehand.

We will also follow all privacy rules outlined by the University of Leeds (https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf) and the Heath Research Authority (https://www.hra.nhs.uk/information-about-patients/).

If you would like further information about how the University of Leeds protects your information you can:

- Email the University Data Protection Officer: dpo@leeds.ac.uk.
- Ask a member of the research team (details are below).
- Call us on **0113 343 2732**

What will happen to the results of the study?

I am happy to share a summary of the results of the study with you. If you would like a copy please speak to the staff member who approached you about the study. Once they let me know I will give them a copy of the results to pass to you.

At the end of the study the results will be written up as part of an educational qualification and may be published in a peer reviewed article or presented at conferences and team meetings. Published material may include some of your quotes from the interview, but I will remove any specific information about you so that you will not be identifiable. The results will also be available at the University of Leeds Library in 2022.

What if something goes wrong?

In the unlikely event that you are unhappy with the way that the study is conducted, a complaint mechanism is available to you. In the first instance please contact Dr Tom Isherwood, t.m.isherwood@leeds.ac.uk.

If you feel distressed after your interview, we suggest you access the following sources of support:

- If you feel you can, perhaps initially discuss any issues with a member of your care team.
- Contact your GP
- Contact your local Patient Advice and Complaints Services (Telephone: 01274 251440)

Who has reviewed the study?

The study has been approved by Yorkshire & The Humber - South Yorkshire Research Ethics Committee (REF: 20/YH/0153).

What if I have questions about the project? Contact details for further information:

If you require any further information then you can contact me or the rest of the research team using the details below:

Email: **umkpa@leeds.ac.uk**   Telephone: **0113 343 2732**

Krisna Patel (Psychologist in Clinical Training)
Clinical Psychology Programme
Leeds Institute of Health Sciences
University of Leeds
Leeds, LS2 9NL

Name: Dr Tom Isherwood
Job title: Admissions Tutor & Deputy Clinical Director

Email address: **t.m.isherwood@leeds.ac.uk**   Telephone: **0113 343 2732**
Leeds Institute of Health Sciences
University of Leeds
1095, Worsley Building
Clarendon Way
Leeds
LS2 9NL

Name: Dr Alastair Cardno
Job title: Senior Lecturer in Psychiatry

Email address: **a.g.cardno@leeds.ac.uk**   Telephone: **0113 343 2732**
Division of Psychological and Social Medicine
Leeds Institute of Health Sciences
Faculty of Medicine and Health
University of Leeds
Level 10, Worsley Building
Leeds LS2 9NL
UK

Name: Dr Anita Brewin
Job title: Consultant Clinical Psychologist, Head of Psychological Therapies in BDCFT

Email address: **anita.brewin@bdct.nhs.uk**   Telephone: **07738977326**

Thank you for spending the time to read and consider this study.

Please keep this information sheet.

Appendix IV: Consent Form

NHS
Bradford District Care
NHS Foundation Trust

UNIVERSITY OF LEEDS

Participant Consent Form

Title of Project: <u>An exploration of the experience and understanding of psychosis in a South Asian population: An Interview Study.</u>

Name of Researcher: Krisna Patel
IRAS Project ID: 275905

Please initial
boxes below:

1. I confirm that I have read the information sheet dated 28/05/2020 (version 1.5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without my medical care or legal rights being affected.

3. I understand that the interview will be audio recorded and that it will be transcribed by someone other than the person who interviewed me and that this will be kept confidential.

4. I understand I will have up to one week after each interview to withdraw my data. After this time the information will be anonymised, which means my name will be removed and I will not be identifiable.

5. I understand that anonymised quotes from my interview may be used in the research write-up.

6. I understand that if there are any significant concerns regarding risk to myself or somebody else, confidentiality will be breached and this information will have to be shared.

7. I understand that the individuals from University of Leeds, regulatory authorities and the NHS Trust may look at the research study to check it meets the research standards required.
   P.T.O.

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes.

8. I consent to staff from the early intervention services being approached by the researcher to obtain some additional information about me, as described in the information sheet.

☐

9. I understand that the supervisors of the research may read my anonymised interview.

☐

10. I understand my consent form, digital and transcript data will be held securely at the University of Leeds for 3 years, from the completion of the project and then destroyed securely.

☐

11. I agree to take part in this interview.

☐

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Trainee
Clinical Psychologist   Date   Signature

Email: **umkpa@leeds.ac.uk**   Telephone: **0113 343 2732**

Krisna Patel (Psychologist in Clinical Training)
Clinical Psychology Programme
Leeds Institute of Health Sciences
University of Leeds
Leeds, LS2 9NL

Appendix V: Instructions for transcriber

Instructions for transcriber

- Use Calibri (bold) size 12

- Use double-spacing.

- Use margins of 5cms on either side of the page to allow for notes to be made.

- Number each line.

- Number each page.

- Mark when the tape is not audible i.e. [inaudible, time stamp].

- Indicate when the interviewer (I) is talking and when the participant (P) is talking.

- Use a new line when a different person starts speaking.

- Remove all names (and reference to place) used in the interview. Therefore, the

  interviewer is known as I; the participant is known as P; any other names can be

  referred to as [name] and places as [places] as appropriate.

- Use appropriate punctuation; i.e. a question mark when a question has been asked,

  a full stop if the conversation topic changes.

- Record any pauses (less than one second) in conversation using (.)

- Record gaps (of more than one second) with [.]

- Record exactly what is said by each person as they say it. This includes any

  hesitations (e.g. erm, err), recurring phrases (e.g. you know, I mean, like, etc.), and

  pauses as they occur in the conversation.

- Do not record anything that has not been said, even if this makes the meaning of

  what is said difficult to understand.

Appendix VI: Ethics approval

Dr Alastair Cardno
Division of Psychological and Social Medicine
Leeds Institute of Health Sciences
University of Leeds
LS2 9NL

Email: approvals@hra.nhs.uk

24 June 2020

Dear Dr Cardno

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

Study title:	**An exploration of the experience and sense-making of psychosis in a South Asian population: An Interpretive Phenomenological Analysis.**
IRAS project ID:	**275905**
Protocol number:	**N/A**
REC reference:	**20/YH/0153**
Sponsor	**University of Leeds**

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

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

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

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

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

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

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:
- Registration of research
- Notifying amendments
- Notifying the end of the study

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

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

Your IRAS project ID is **275905**. Please quote this on all correspondence.

Yours sincerely,

Rebecca Evans

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Miss Jean Uniacke*

List of Documents

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

Document	Version	Date
Covering letter on headed paper		17 June 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor indemnity letter]		20 April 2020
Interview schedules or topic guides for participants [Interview topic guide]	V1.5	20 April 2020
IRAS Application Form [IRAS_Form_17062020]		17 June 2020
IRAS Application Form XML file [IRAS_Form_17062020]		17 June 2020
IRAS Checklist XML [Checklist_17062020]		17 June 2020
Organisation Information Document [Organisation information document]	V1.1	01 April 2020
Other [Protocol to minimize and manage the risk of participant distress]	V1.1	23 March 2020
Other [Staff information sheet]	V1.3	16 March 2020
Other [Study approval letter from head of service]		04 December 2019
Participant consent form [Participant consent form]	V1.5	28 May 2020
Participant information sheet (PIS) [Participant Information Sheet]	V1.5	28 May 2020
Research protocol or project proposal [Research protocol]	V1	24 February 2020
Schedule of Events or SoECAT [Schedule of events]	V1.1	01 April 2020
Summary CV for Chief Investigator (CI) [Summary CV for CI]		10 February 2020
Summary CV for Chief Investigator (CI) [Summary CV for CI]		12 February 2020
Summary CV for student [Summary CV for student]		10 February 2020
Summary CV for supervisor (student research) [Summary CV for supervisor (Dr Cardno)]		12 February 2020
Summary CV for supervisor (student research) [Summary Cv for supervisor (Dr Isherwood)]		01 January 2007

Yorkshire & The Humber - South Yorkshire Research Ethics Committee

> <u>Please note</u>: This is the
> favourable opinion of the
> REC only and does not allow
> you to start your study at NHS
> sites in England until you
> receive HRA Approval

22 June 2020

Dr Alastair Cardno
Division of Psychological and Social Medicine
Leeds Institute of Health Sciences
University of Leeds
LS2 9NL

Dear Dr Cardno

Study title:	**An exploration of the experience and sense-making of psychosis in a South Asian population: An Interpretive Phenomenological Analysis.**
REC reference:	**20/YH/0153**
Protocol number:	**N/A**
IRAS project ID:	**275905**

Thank you for your letter of 17 June 2020, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

The Committee recommends that the "XX" in the PIS is replaced with the REC details:

Who has reviewed the study?

The study has been approved by XX

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.</u> Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

<u>Registration of Clinical Trials</u>

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. <u>Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs)</u>, except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: <u>Reporting requirements</u>

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

•   Notifying substantial amendments
•   Adding new sites and investigators
•   Notification of serious breaches of the protocol
•   Progress and safety reports
•   Notifying the end of the study, including early termination of the study
•   Final report

The latest guidance on these topics can be found at
https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper		17 June 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor indemnity letter]		20 April 2020
Interview schedules or topic guides for participants [Interview topic guide]	V1.5	20 April 2020
IRAS Application Form [IRAS_Form_17062020]		17 June 2020
IRAS Checklist XML [Checklist_17062020]		17 June 2020
Other [Study approval letter from head of service]		04 December 2019
Other [Protocol to minimize and manage the risk of participant distress]	V1.1	23 March 2020
Other [Staff information sheet]	V1.3	16 March 2020

Participant consent form [Participant consent form]	V1.5	28 May 2020
Participant information sheet (PIS) [Participant Information Sheet]	V1.5	28 May 2020
Research protocol or project proposal [Research protocol]	V1	24 February 2020
Summary CV for Chief Investigator (CI) [Summary CV for CI]		10 February 2020
Summary CV for Chief Investigator (CI) [Summary CV for CI]		12 February 2020
Summary CV for student [Summary CV for student]		10 February 2020
Summary CV for supervisor (student research) [Summary CV for supervisor (Dr Cardno)]		12 February 2020
Summary CV for supervisor (student research) [Summary Cv for supervisor (Dr Isherwood)]		01 January 2007

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 275905   Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

[signature]

pp
Dr Ian Woollands
Chair

Email: southyorks.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Miss Jean Uniacke

Appendix VII: R&D approval

John Vertannes
Confirmation of our Capacity and Capability
To: Krisna Patel

3 August 2020 at 11:54

Good morning Krisna,

Please find attached our completed Organisation Information Document this serves as confirmation of our Capacity and Capability to open this study.

Please reply to this and confirm that you would like this study opened at our site

Thank you

hello my name is…

John Vertannes
Data, Information Systems and Governance Officer
Research Management Office
Bradford District Care Foundation Trust
Osprey House | Lynfield Mount Hospital | Heights Lane | Bradford | BD9 6DP

Appendix VIII: Approval from Trust Head of Psychology

NHS
Bradford District Care
NHS Foundation Trust

Our ref: AB/KP

Psychological Therapy Services
c/o New Mill
Victoria Road
Saltaire
Bradford
BD18 3LD

4/12/19

PRIVATE & CONFIDENTIAL

Tel: 07738 977326
Email: anita.brewin@bdct.nhs.uk

To whom so ever it may concern,

Re: An exploration of the experience and sense-making of psychosis in a South Asian population: An Interpretive Phenomenological Analysis

I would like to confirm that as an organisation BDCFT is happy to support this D.Clin.Psychol. thesis being conducted by Krisna Patel, subject to ethical approval. Our EIP service is aware of the study and prepared to work with Krisna in identifying suitable candidates to participate in the research. I will take the role of PI for this study, providing Krisna with supervision/support as required.
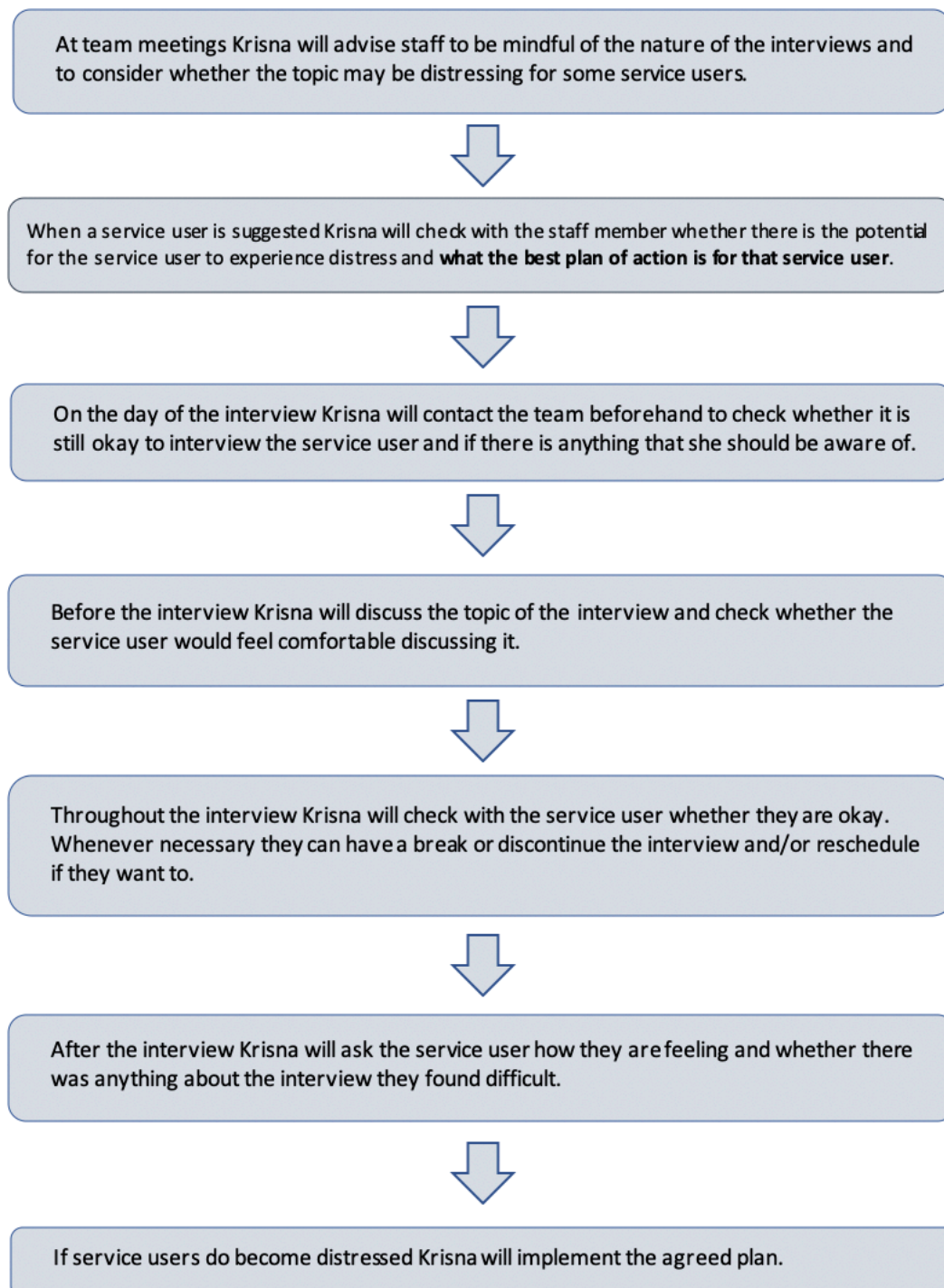
Yours sincerely

Dr Anita Brewin
Consultant Clinical Psychologist
Head of Psychological Therapies (BDCFT)

Appendix IX: Protocol to minimise and manage the risk of participant distress

Protocol to minimize and manage the risk of participant distress

At team meetings Krisna will advise staff to be mindful of the nature of the interviews and to consider whether the topic may be distressing for some service users.

⬇

When a service user is suggested Krisna will check with the staff member whether there is the potential for the service user to experience distress and **what the best plan of action is for that service user.**

⬇

On the day of the interview Krisna will contact the team beforehand to check whether it is still okay to interview the service user and if there is anything that she should be aware of.

⬇

Before the interview Krisna will discuss the topic of the interview and check whether the service user would feel comfortable discussing it.

⬇

Throughout the interview Krisna will check with the service user whether they are okay. Whenever necessary they can have a break or discontinue the interview and/or reschedule if they want to.

⬇

After the interview Krisna will ask the service user how they are feeling and whether there was anything about the interview they found difficult.

⬇

If service users do become distressed Krisna will implement the agreed plan.

P: umm, and I was like, you know I'm not gonna get help that I need and, because number one obviously like mental health is such a taboo in Asian communities

I: mm

P: and I don't know about other communities but in the Pakistani community, it doesn't exist. So, um, if you're depressed, it doesn't exist. If you've got anxiety, it doesn't exist. If you've got mental health issues, it doesn't exist. Because, I mean specially like in my family, it's very, at the forefront. So, specially like my father, it was like if your father's like depressed or like with my mental health issues he used to be like, 'Well, she's. . . it's acting'

I: mm

P: it's not, you know 'it's not real', and 'she's just doing it for attention'. So, he used to put it down to attention seeking and er, but obviously it's not. So, um, even like today until this day he doesn't, he won't acknowledge it that there's something wrong with me, mentally. He just thinks that er, I'm having one of, I'm having a tantrum or, and I'll be okay. And, you know if, if they leave me to it, you know I'll be all right. So, he doesn't, he doesn't acknowledge that fact. I don't know. . .why but er, he just, he just doesn't believe it. So . . . and I mean from what I've seen, I've also seen it with a lot of like the extended, like where I live here cause it's, it's a pretty Asian populated area. So, even there it's the same. So, it's like they don't know that I suffer from it. But it's like if we're having a conversation, and a conversation does come up-and it does come up on mental health, the first thing that always comes

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Was not going to get the help that she needed
Perception of MH in SA community –
Number one" – most importantly Taboo – forbidden, stigmatising, not openly spoken about. She names taboo, which is really interesting as it suggests that there is a sort of implied acceptance that some people have these problems/experiences/differences, but that there is something shameful or wrong about

Specific experience of Pakistani community *– it doesn't exist – ignored, not spoken about, or not a concept that is accepted as part of the human experience. A denial of their existence.*
Anxiety/depression – psychological/medical language – MH medical phenomena
Repetition of "it doesn't exist"- emphasis on the level at which it is not accepted, dismissed as not genuine. Going from specific MH difficulties to general terms MH concerns – unyielding response to MH
Disbelief of MH very apparent in her family – especially father who labelled her MH problems as "*acting*" – putting it on, attention seeking?

"it's not real" – disbelieving and putting it down to attention seeking.

"*but obviously it's not*" - Not a belief that she held.
Sense of time – even after all of her experiences, father won't acknowledge/accept her difficulties as legitimate - invalidation of her experiences.
"*Something wrong with me, mentally*" – negative, deficit, difference? Internalised belief about her MH difficulties.
"*tantrum*"- she is being treated like a child, infantilising her difficulties? Linked to attention seeking?
Infantilising response – passivity - leave her alone and she'll be fine, not actively intervening or supporting
Repetition of father not acknowledging MH problems as a fact. Sense that she has searched for why - Unclear about why her father holds this belief.
Belief held in in "extended" community – reflecting on the local areas Asian population.
Sense that same belief is held by general Asian community.
Sense of secrecy/hiding – stigma?

MH is something that is discussed but it is dismissed as something not genuine, real.

MH exists on the periphery of SA communities awareness
Deeply engrained tradition of shame and hiding MH in SA community

MH as inner experience/personal struggle
MH distinct from behaviour – psychological/medical issue
MH as an invalid/inauthentic concept in SA community

Interpersonal experience – others denial of MH or misattribution/reattribution of difficulties

MH as dismissed/infantilised
The problem lies with her/personalises struggles.

Others invalidating authenticity of struggle - MH as attention seeking

Social rejection by family

Stigma of MH and invalidation of authenticity of difficulties.
Hiding MH difficulties from others

2

Appendix XI: Quality Assurance

1. *Owning one's perspective* - a research journal was kept to reflect on the researcher's theoretical stance, personal orientation, experience and values.

2. *Situating the sample* - there is a transparent description of the recruitment process, including participants who declined. For the final sample, descriptive details are provided for each participant, alongside a pen portrait.

3. *Grounding in examples* - the use of verbatim extracts from the data to support the themes that have been identified and to capture the richness and nuance of the participant's narrative.

4. *Credibility* - ensured by obtaining multiple perspectives in the following way:

   - Member checking to validate interpretations during the interview process. By asking for clarity, checking understanding and assurance of interpretation.
   - Keeping a reflective journal during the study, noting thoughts, feelings and reflections on the research, biases and assumptions.
   - Repeated reading of transcripts and iterative analysis of data.
   - Via supervisory discussion of interpretation of data.
   - Via discussion of interpretation process with IPA expert.
   - Use of a cultural consultant to further interrogate interpretation to increase *trustworthiness*.

5. *Coherence* - data was analysed systematically and presented coherently. In order to avoid discreet representation of themes which do not relate, themes were grouped under subordinate and superordinate categories that are supported by extracts from the participants, to increase transparency.

6. *Accomplishing general versus specific research tasks* - distinctions between a general phenomenon that appears to relate to the other findings in the literature and something that is specific to an individual case are made explicit in the results and discussion chapters.

7. *Resonating with readers* - basic demographic information and pen portraits are provided to help the reader understand the participants experience in a meaningful way and reflect on identified themes and associated verbatim extracts within the context of their complete narrative.

Appendix XII: Reflections

Prior to interviews

Initial assumption is that culture and being South Asian will have an impact on psychosis - what about those who don't consider it a factor, largely the initial discussion were around the impact on the content of unusual experiences, and on belief models.

Initial general assumptions - isolation, rejection and stigma, racism and discrimination, poor cultural understanding by others, staff unaware of spiritual beliefs, anxious, misunderstood, bullied.

Where do illness beliefs come from?

Generally the experience will be negative, and around struggles, loss etc.

Too unwell to participate? Worry that I will make something worse by not being sensitive to things. How does this link to insight, do you need insight to reflect? What does insight mean to different people?

Although I knew the experiences where going to be difficult to discuss (indicated by discussion of distress in ethics application) I had prior experience and felt like I knew when to draw the line.

Experience of culture will be around gender stereotypes, rejection, fear of person, social stigma – perceived to be different, weird.

Service users withdrawing because they feel in danger, family friends withdrawing because they feel at risk?

Psychosis associated with deficit or life being on hold?

Experience of inpatient admission as negative, scary, feeling 'done to'.

Homogeneity of sample – keep it broad but there is a huge degree of variation between and within the South Asian community, would my research be useful or applicable? Would this research be transferable? EIS or hearing voices group, or other groups? Will this make it to heterogenous? What would that mean?

Initial discussion around caste system – does this apply to Indian people only? What about Sikh people who have quashed the caste system, as far as I am aware? My limited knowledge about caste systems outside of Indian one.

Gender differences in experiences – is this something to be explicitly explored at this stage? Whose experiences – service user, families, EIS staff?

Language and IPA – what happens if participants use another language?

Lack of research in SA, but even more so in certain groups e.g. Bangladeshi – what about people who don't want to take part, use of gatekeepers – recommending those that engage with the service, or are talkative, they have a better relationship with?

During interviews

Participants felt comfortable sharing experiences, and opening up. Diversity in experiences, but what about group analysis, common themes?

How am I going to balance giving voice to each story and bringing it together. What will be the final split of individual analysis and group (70:30; 50:50; 30:70??).

Some topics have been unsurprising, given my questions and fit with the literature but there is something different here too and each person story is unique.

Struck by the impact of bicultural identity has on experiences, even though I am bicultural and the research I have read about it notes it's impact.

Stigma and shame has come up but within different, and unexpected contexts. Stigma can be something that is mentioned as a common effect of mental health difficulties, but hearing each person's story and experience of it has bought it to life in a different way.

Complexity in their illness frameworks, not stable, and there is a back-and-forth process of figuring out what was happening.

Interview data for one participant may not be 'usable'.- what does this mean?, poverty of speech, is it fair to not include in final sample? Couldn't say what sense she made of these experiences ("I don't know" / "not sure".) Interview was punctuated by very long pauses. Was not taking medication when we spoke, although she hadn't told her parents this ("They'll worry, so that's why I try to keep things to myself."). She still spoke of some things that others did: Secrecy and interpretation:

> **P: they don't want no one else to know, coz if one finds out they'll all find out. I don't want my cousins to find out about a lot of this.**
> *I: I see, why don't you want your cousins to know?*
> **P: they'll just make fun, they'll just make fun of us**
>
> *I: okay, what do these experiences mean to you?*
> **P: that summit's wrong with me and that it's probably happening because I'm getting less sleep and I've been over thinking then, about the voices and why I'm not getting sleep, then I take more medication that, then I need to.**
>
> (22, British Pakistani, FEP).

Not much in respect of content on experiences as spiritual or religious.

Interesting that spiritual illness belief is default but considered alternative.

Pleased that some people felt their experiences have resulted in positive transformation – I was surprised by this, indicating my assumptions that psychosis would be debilitating, or having a lasting negative impact. Not many participants associated with chronicity.

Some participants spoke of employment and plans to start university – I was struck by how they were able to do these things during and after such overwhelming experiences.

I was shocked when participants told me they were experiencing hallucinations during the interview, as I couldn't tell – my assumption that they would be easily distracted, couldn't go about their day and hear voices.

What is it about the patriarchal system – good, bad?

Gender roles – are they helpful, how are they impacting help-seeking and expectations?

When sharing experiences of trauma, I worried I had probed, was this appropriate, balancing sensitivity to distress and the research. Difficult to not take a clinical role. Is it any of my business- am I being nosey?

Listening back to interviews, I realised there are so many avenues to take, my experiences or interests privileging certain topics over others?

Some interviews seem to flow better than others. Some felt a bit disjointed. My confidence did increase over the course of interviewing, helped me relax.

Some participants were experiencing things but were able to reflect on experiences, but some peoples unusual beliefs were tangled in their sense-making – did I miss this during the interview and probe too much – asking several times how they have made sense of it, rather than accepting they are still trying to make sense of it.

How much about me affected how the participants engaged with me. Salma was very open about her trauma, as was Dalil – is this because we are both Asian or I was female? Did my ethnicity put people at ease, or were they worried about judgement? Did some participants think I would get all of their cultural references because we are both SA? Did I pick up on all of these to ask what the participant meant, rather than assuming? For example, when

people used terms like Jinn's, izzat, taweez? How did my gender impact engagement? Did it help or did people feel they had to hold back? Did my clinical/researcher role help sometimes, or did people hold back – like Amina and Nazreen where I sensed they were embarrassed to talk about spiritual interpretations or drug use.

During analysis

Underestimated the challenges and time it took for analysis.

Due to the availability of transcripts, I was initially working with four transcripts, and decided to analyse each on up to the point of identifying emerging themes. My reasoning behind this was to reach a certain point with each transcript before going back to the first transcript and starting the next step. After a meeting with an IPA consultant, I was advised to go back and complete analysis of each transcript, before moving on to another. I did this for the remaining four from the get go. In hindsight, I don't feel it made a significant difference to the analysis as I was able to treat each transcript independently of the others. I initially listened to each audio with the transcript to make any corrections.

During analysis, I found the process of listening to the audio once without the transcript and then twice or more with and then reading my reflections on the interviews were enough to take me back to how it felt to interview that person. I was also able to note particular recollections during this.

Analysis of Dalil's account seemed more challenging than others. Depth of analysis seemed harder to achieve which is potentially a reflection of his disjointed account. There are lots of interesting avenues he offers but the synthesis may have been limited because the way he presented that information was incoherent and not easy to synthesise.

Completing each analysis, did help with feeling like I was making progress and becoming more familiar and confident with the process.

Although the double-hermeneutic process was in a way an attraction of IPA, it raised several challenges and implications. Initially, my accounts of the participants experiences cautioned on the descriptive side, but as I began to be more interpretative and discussion with supervisors I began to worry I was moving to far away from the participants narratives and too close to abstract interpretations.

During the interviews, and the analysis process I realised, to my disappointment, that I still held a lot of power, for example, where I prompted participants and where this took them. What ideas and experiences I privileged because it was relevant to what I was researching or something about their experiences that resonated with me. One example was Asim's reflections on his religion and culture and his identity. Something that I was interested in but also on reflection resonated with my because of my own relationship with religion and culture. Another example was the idea of a patriarchal family system and gender roles and how these impact the participants experiences. I enjoyed the interview process immensely. Am I giving enough space to the voice of the participants, rather than my interpretation – what is being lost?

Where people are when I interview them, some seem to be searching for an explanation, others are still experiencing things are not quite ready to reflect, some feel they have moved passed their experience and can reflect on it.

Impact of acculturation – struck by Dalil's comments of 'being British" and where this leaves him across the cultures he inhabits.

Struck by some participants reflections on being bicultural.

Some participants keen to separate religion and culture. Religion seen as a protective factor (faith), culture for some reflected barriers to help-seeking and support.

Difficult to strike a balance e.g. the role of trauma and PTSD, in clinical practice interpretations would be tentative and based on joint formulations, but research interpretation seems like the power is with me to make interpretations, label the themes, speak about what is salient. I worry if the participant read it, would they see their story? Speaking to Razia has been helpful, to discuss initial thoughts and her reflections on the analysis.

Several times, where I directed the interview in a different direction, because the participant mentioned two things and I picked one over the other, and noticed only when I listened to the audio after the interview. Realise that although I tried to keep the research questions broad, I influenced what the participant spoke about and which topics they bought up, and thus the themes that I eventually identified.

Difficult navigating the split between individual analysis and group analysis. Initially, I intended to focus on the group analysis. As I wrote up the individual analysis, I realised that these stories were rich and didn't want to risk losing them. I was mindful of the time participants had given, and the emotion that these narrative captured. Some experiences were difficult to recall for participant, but they shared them with me, and that would be lost if I was to focus solely on group analysis. I wondered about who would the group analysis be for – would they reflect the transferability rather than idiography? I decided that the final version will include an individual analysis, followed by a group analysis. I reflected that if we were to publish this research, it would focus on the common themes that weaved through these stories, but there should be a document that captures these individual lived experiences.

Power is something that comes up in different ways for each participant. Power is something I am interested in – is this also why it resonates with me and why it is more salient?

I feel that having read through the transcripts several times, I have been left with more questions than answers.