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EXPERIENCES OF PSYCHOSIS AND HEARING VOICES IN THE UK FROM AN ETHNIC MINORITY PERSPECTIVE

Section A: What are BAME Individuals' and their Families' Experience of Psychosis in the UK? – A Systematic Review
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Section B: Hearing Voices within a Western Society from an Ethnic Minority Perspective: Navigating Explanations and Culture
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Statement to Examiners

Due to the COVID-19 pandemic, a lot of the hearing voices groups and non-NHS organisations were temporarily shut down. This significantly impacted the recruitment process, and as a result I was only able to recruit four participants. A lot of effort was put into recruitment and I tried to recruit via various pathways, however, this was not fruitful.

I started the IRAS application in May 2021 to enable me to recruit via NHS services. However, due to my external supervisor leaving the service, having to find a new local collaborator within the service, supervisor going on maternity leave, local collaborator going on annual leave, and the trust head of research being on significant time off, I received confirmation of capacity only in December 2021. We attempted to recruit via NHS for approximately 3 months. However, after not being able to recruit a single participant via NHS, we decided to withdraw the IRAS application and complement the existing interview data with published stories from books.

This ‘new’ project was approved and received Salomons’ ethics amendment in March 2022. Due to the limited time between approval and submission, quality measures such as respondent validation is still in progress.

Summary of MRP

Section A: This review aimed to evaluate qualitative reports of BAME individuals' and their families' experience of psychosis in the UK. Six databases were searched, identifying eleven studies which were critically reviewed. A thematic synthesis of the findings highlighted six themes: experiences of psychosis that did not conform to the western medical model, the rigidity of the medical model used within MH services, medication vs. psychological therapy, lack of autonomy, choice and individuality, stigma within services and society, and support and resources required for recovery. The review also outlined various clinical and research implications.

Section B: This study aimed to explore ethnic minority voice-hearers' experiences of being immersed within and navigating Western society and explanations of hearing voices in the UK. Reflexive Thematic Analysis was used to analyse the data (four interview and eight published stories). Six themes were developed: the individuality of hearing voices explanations, clash of cultural identities, challenges of hearing voices within current society, labels – forceful and powerful, real choice vs. illusion of choice, and recovery is a continuous process. The findings are discussed in conjunction with existing literature. The limitations of the study, research recommendations, and clinical implications are also highlighted.

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Section A: Literature Review

What are BAME Individuals’ and their Families’ Experience of Psychosis in the UK? – A Systematic Review

Word Count: 7996 (67)

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Abstract

Introduction: Black, Asian and Minority Ethnic (BAME) individuals in the United Kingdom (UK) are more likely to receive a psychosis diagnosis, experience compulsory detention, have criminal justice involvement, and be prescribed antipsychotics. However, BAME individuals are less likely to access mental health (MH) services and often access services at a later stage. It is important to understand people's experiences in relation to this disparity, to better understand the factors that may be impacting the quality of care.

Aim: To evaluate qualitative reports of BAME individuals' and their families' experience of psychosis in the UK.

Method: A systematic literature search was conducted by searching six databases, identifying eleven studies. These studies were critically reviewed, and a thematic synthesis was used to collate key findings into themes.

Findings: Six themes were derived: experiences of psychosis that did not conform to the western medical model, the rigidity of the medical model used within MH services, medication vs. psychological therapy, lack of autonomy, choice and individuality, stigma within services and society, and support and resources required for recovery. The review also highlighted the scarcity of research in this field and the lack of diversity within the samples, prompting the need for further research.

Keywords: Psychosis; BAME; Qualitative; Service-user; Family

Introduction

Mental Health and Ethnic Minority Groups in the UK

In the United Kingdom (UK), the reported prevalence of mental health (MH) difficulties for Black, Asian and Minority Ethnic (BAME) individuals is higher than White British individuals (Baker, 2020). Despite this increase, individuals from BAME communities are up to 20% less likely to access MH services (Baker, 2020). Several factors have been hypothesised to explain this disparity.

Racism, for example, has been linked to a higher rate of receiving a MH diagnosis amongst BAME communities, especially for Black individuals (Bhui et al., 2003; Byrne et al., 2020), and to the higher risk of developing MH difficulties as a result of increased feelings of distress, vulnerability, and alienation (Boydell et al., 2001; Karlsen et al., 2005; Van Os et al., 1996). In relation to accessing services, the fear of being detained and mistrust of MH services may result in individuals from BAME communities, especially Black communities, accessing MH services at a later and more severe stage (e.g. Byrne et al., 2020; Fernando, 2003; Keating & Robertson, 2004). Keating and Robertson (2004) theorise that the combination of Black individuals' mistrust of services and the stereotypes and prejudices regarding Black individuals perpetuated within MH services, a "circle of fear" (p.440) is created which acts as a vicious cycle that maintains barriers to help-seeking.

Additionally, stigma is reported to be a barrier due to MH being a taboo subject in many cultures and is perceived to bring individuals and their families shame, especially if contact with services leads to being detained (Mantovani et al., 2016). Research also suggests many individuals from BAME communities report feeling misunderstood or judged by MH services because of their culture, acting as a barrier to seek help in the future (Islam et al., 2015).

It is important to note that the use of the term "BAME" has its limitations as it positions all minoritised individuals into one group, without taking into consideration the variability and diversity of each group. This also positions individuals as being different from the majority, and may promote the narrative that the problem lies within these communities instead of wider systems and institutions (Milner & Jumbe, 2020). However, due to the pervasive use of this term within existing literature and the limited volume of research within this topic, the term BAME was used throughout this review to highlight the common experiences, inequalities and barriers faced by many individuals from ethnic minority groups. Nevertheless, it is important to keep in mind the variability between groups whilst reading this review.

Psychosis and BAME Communities

Psychosis, in particular, has a higher disparity between White British and BAME communities. Research suggests that BAME individuals, especially those who identify as Black, are more likely to receive a psychosis diagnosis (Boydell et al., 2001; Halvorsrud et al., 2019), be admitted to hospital for psychosis (Mann et al., 2014; Van Os et al., 1996), and experience compulsory detention (Halvorsrud et al., 2018; Mann et al., 2014). For example, Mann and colleagues (2014) found that across four early intervention services for psychosis in London, Black service users were three times more likely than White British service users to be admitted to hospital. This disparity was even greater for women, with Black women showing up to eight times increase in hospital admission as compared to White women. The UK-based Aetiology and Ethnicity in Schizophrenia and Other Psychoses (ÆSOP) study found that when compared to the White-British population, the recorded incidence rate for psychosis was up to 9.1 and 5.8 times greater for Black Caribbeans and Black Africans respectively, and up to 3.5 times greater for Asians (Fearon et al., 2006).

Although the prevalence rate of a psychosis diagnosis in BAME communities is higher, this higher prevalence is not seen in countries where those cultures are the majority (Bhugra, 2004). Therefore, the higher prevalence is not due to biological vulnerabilities amongst certain ethnic groups, but might instead be influenced by experiences of being an ethnic minority or the possible additional stressors and loss of resources as a result of migration (Bhugra, 2004). Boydell and colleagues (2001) found that the disparity in psychosis diagnosis was greater in white-dominant areas, and hypothesised that the increase in psychosis diagnosis amongst the BAME group may be attributed to social factors such as racism from individuals and institutions. This is supported by Karlsen and colleagues (2005) who found that the risk of meeting the criteria for a psychosis diagnosis was higher in individuals' who reported higher experiences of racism.

The Traumagenic Neurodevelopmental Model of Psychosis posits that childhood adversities, which may include experiences of racism, may produce vulnerabilities as a result of changes to the developing brain, which may increase the likelihood of experiences associated with a psychosis diagnosis (Read et al., 2001; Read et al., 2014). National surveys conducted in America and UK found that having two or more traumatic experiences significantly increased the risk of a psychosis diagnosis, and the risk increased with additional traumatic experiences (Shevlin et al., 2008). However, Shevlin and colleagues (2008) only investigated trauma related to sexual abuse, assault, serious injury and violence at home or work. Hence, it is unclear whether this finding could be applied to experiences of racism. Nevertheless, considering racial inequalities in the UK across various sectors (Byrne et al., 2020), it is important to consider the possible impact of racism in relation to psychosis.

Institutional Racism and Psychosis

Critical Race Theory (CRT) "examines the interconnected relationship between race, power and the law" (Moodley et al., 2017, p.81). According to CRT, racism is something that is embedded and has become normalised within society (Moodley et al., 2017). In line with this, Macpherson (1999) defines institutional racism as “the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin [...] through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantages minority ethnic people” (p.28). It has been suggested that MH services, especially psychosis services, may be unconsciously perpetuating institutional racism (Byrne et al., 2020).

A meta-analysis by Halvorsrud and colleagues (2018) found ethnic inequalities within pathways into MH services, highlighting that BAME individuals, especially Black individuals, have a higher risk of compulsory admission, more criminal justice system involvement, and less frequent contact with general practitioners. Findings from the ÆSOP study also revealed that Black Caribbean individuals had a higher rate of being admitted to MH services through police involvement and were also more likely to experience worse clinical and service outcomes (Morgan et al., 2018). Moreover, Das-Munshi et al. (2018) found that BAME individuals were more likely to be prescribed depot antipsychotics injections and less likely to be offered cognitive-behavioural therapy.

It is important to acknowledge and understand these inequalities, as the impact of institutional racism can be catastrophic. For example, the enquiry into the death of David Bennett, a young Black man, found institutional racism to be a leading contributor to his death (Norfolk, Suffolk, and Cambridgeshire Strategic Health Authority, 2003). Therefore, as emphasised by CRT, it is important we do not view racism as only an act of individual prejudice, but also acknowledge the systemic failings which consistently impact BAME individuals (Moodley et al., 2017).

Aim and Rationale of This Review

The core values of the National Health Service (NHS) in the UK include values around “improving lives”, “working together for patients”, “everyone counts”, and “commitment to quality of care” (Department of Health and Social Care [DHSC], 2021, para.15-20). Considering the possible ethnic inequalities and its impact on individuals’ help seeking behaviour and engagement, it is important to further understand people’s experiences of psychosis in the UK. Although quantitative research tells us that there are disparities in care, qualitative research is also important to help us better understand people’s experiences and how various factors may be impacting the quality of care. However, a systematic review of these qualitative studies does not appear to have been conducted yet. Additionally, families play an important role in an individual’s journey with psychosis (Addington & Burnett, 2004), and thus their experiences may also provide an important insight into individuals’ experiences.

The aim of this review was to synthesise qualitative reports of BAME individuals’ and their families’ experience of psychosis in the UK. This review aims to understand the factors that may impact people’s experiences, and what barriers may be currently impacting access and engagement with MH services in the UK. A qualitative review is selected to explore people’s subjective experiences and the qualitative design is also especially equipped to investigate complex issues and dynamics such as feelings and experiences of injustice and discrimination (Chakraborty et al., 2009). To the author’s knowledge, there are currently no reviews addressing these aims, highlighting a gap in the literature.

Method

Literature Search

Six electronic databases were searched in September 2021. The databases searched were Applied Social Sciences Index and Abstracts (ASSIA), Medline, PsycInfo, PubMed, Web of Science and EBSCOhost. The list of search terms used are summarized in Table 1. No date restrictions were applied to the searches.

Articles retrieved from the databases were screened for duplicates. Titles and abstracts were then screened to identify relevant articles. References of selected articles were also screened to identify any articles that may have been missed from the database searches. Figure 1 summarises the screening and selection process. The following inclusion and exclusion criteria were used during selection process.

Inclusion Criteria

- Peer-reviewed studies conducted in the UK. The peer review process is suggested to be a process that verifies the quality of the research (Braun, 2004).
- Qualitative research.
- Explores the experiences of BAME individuals and/or their family members' experience of psychosis in the UK.
- Written in English.

Exclusion Criteria

- The experiences explored were only intervention focussed (e.g. ways to improve CBT for psychosis rather than experiences of CBT), as this would not address the review's aims.
- Studies which were not psychosis specific.

- Studies that only explored explanatory models of psychosis, and not experiences of psychosis or services.

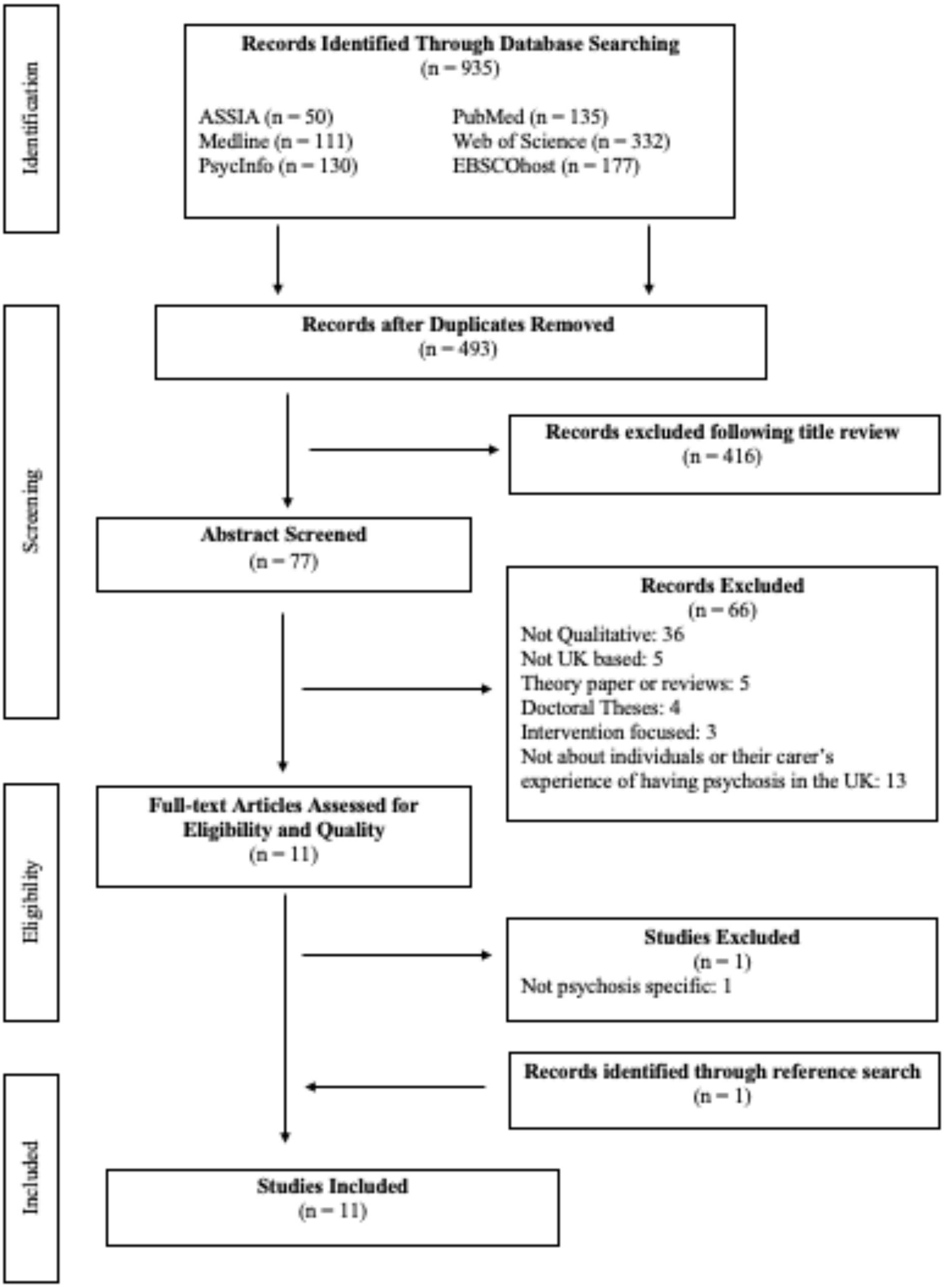
Table 1

Summary of search terms used.

Search Terms		Search Terms		Search Terms		Search Terms
Cultur*	AND	Psychosis	AND	UK	AND	Qualitative*
OR		OR		OR		OR
Ethnic*		Psychoses		Brit*		Interview*
OR		OR		OR		OR
Minority		Psychotic		United Kingdom		Focus Group*
OR		OR		OR		OR
Spirit*		Schizo*		England		subjective experience
OR		OR		OR		OR
BAME		Voice hear*		Scotland		narrative
OR		OR		OR		OR
BME		Hear* Voice*		Wales		stories
OR		OR		OR		OR
Black		Delusion*		North* Ireland		phenomenol*
OR		OR		OR		OR
Asian		Hallucinat*		London		meaning
OR						OR
Caribbean						grounded theory
OR						OR
African						thematic
OR						OR
Religio*						themes
OR						
Chinese						
OR						
Indian						
OR						
Non-West*						

Figure 1.

PRISMA diagram summarising the screening and selection process of the literature search.



Thematic Synthesis

The findings of the selected articles were collated following an inductive thematic synthesis approach as outlined by Thomas and Harden (2008). A thematic synthesis allows people's experiences, perceptions, and motivations to be explored and captured, whilst an inductive approach was chosen allowing the themes to be derived from the data (Braun & Clarke, 2013; Thomas & Harden, 2008). As outlined by Thomas and Harden (2008), the findings of each study were read multiple times and coded line-by-line. As it is not possible to present all the quotes from participants in a journal article, authors may often summarise a group of quotes using their own words. Therefore, these initial codes include direct participant quotations as reported in the studies, and quotations from the authors' description of each theme, to ensure valuable data was not lost. These codes were then analysed and organised into categories, forming descriptive themes which reflect closely what was reported by the original authors. These themes were analysed and interpreted further, forming analytical themes which take into account the reviewer's judgments and inferences (see Appendix A for an illustration of this process).

Review

Eleven studies were selected for this review. These studies are summarised in Table 2. Following the summary of the studies, this review provides a critical discussion of the methodological considerations, and key findings according to common themes. In line with the review aims, for studies which include the experiences of multiple groups of participants (e.g. service users, family members, professionals, members of the public), only experiences of service users and their families are considered.

To assess the quality of the studies, the Critical Appraisal Skills Programme (CASP; 2018) Qualitative Checklist was used as a guide (see Table 3 for a summary and Appendix B for the detailed appraisal). The CASP checklist was chosen as it is suggested to be the most recommended tool to appraise qualitative studies (Long et al., 2020; Ma et al., 2020).

Table 2.

Summary of the eleven studies identified by the literature search, in order of publication.

No.	Study	Relevant Study Aims	Participant Demographics	Data Collection	Analysis	Key Qualitative Findings
1	Chakraborty, McKenzie, & King. (2009)	To qualitatively present a comparison between White British and African-Caribbean individuals' experience of unfair treatment in the UK and its perceived cause.	**Sample:** 20 participants with a diagnosis of a psychotic illness **Age:** 26 – 64 years. **Gender:** 10 Females; 10 Males **Ethnicity** 10 Black Caribbean patients, 10 White British patients	**Method:** Open ended ethnographic interviews **Length:** approx. one-hour **Interviewer**: Young, male Bangladeshi psychiatrist, largely raised in Britain. **Use of interpreters:** Not reported	Interviews were analysed using a "qualitative software package QSR NUD*IST-4". However, it is unclear what type of qualitative analysis was used.	- Both groups described a similar number of experiences of perceived unfair treatment. - Black Caribbean participants were more likely to attribute their ethnicity and racism as the cause of unfair treatment - White British participants were more likely to attribute their mental illness as the cause of the unfair treatment - **Themes and Subthemes reported by the paper:** • Medical: hospital staff; medicine; injections; hospital; therapy • Societal: education; money: work; parental rights; housing; public harassment • Interpersonal: family; partner; friends • Dangerousness: drugs; risk; detention; law • Beliefs: self; disorder; locus; symptoms
2	Penny, Newton, & Larkin (2009)	To explore the treatment experiences of families of Pakistani origin, and their beliefs about treatment and psychosis	**Sample:** 11 family members. Service users were all first-generation British Citizen (parents and grandparents born in Pakistan, service user and siblings born in Britain). **Age:** Not reported **Gender:**	**Method:** Semi-structured interviews **Length:** Not reported **Interviewer:** Interviews were conducted by the first author. Details of interviewer not reported.	Interpretative Phenomenological Analysis (IPA)	**Themes and Subthemes reported by the paper:** - A story of Loss • Sudden realisation • Hope disappointed • Loss and worry - A Social Problem • Problem has a social manifestation • Problem has a social cause • Problem has a spiritual cause • Absence of psychological-psychiatric explanation - Divergent Points on the Path to Change

			8 Females; 3 males **Ethnicity** Pakistani or British Pakistani	**Use of interpreters:** - Three interviews carried out through interpreters, and one through a family member.		• Change should be social and relational • Faith and spirituality • Early intervention is only about medicine • Families and service users are striving for mutual understanding • Care is the family's responsibility
3	Rathod, Kingdon, Phiri, & Gobbi. (2010)	To gain meaningful understanding of the way members (lay and service users) of these minority communities typically view psychosis, its origin and management including their cultural influences, values, and attitudes	**Sample:** Group (G)1: African Caribbean lay people and patients with psychosis with and without experience of CBT. G2: South Asian Muslim lay people and patients with and without experience of CBT G3: CBT therapists G4: mental health practitioners Total number of patients: 15 **Age:** Not reported **Gender:** G1: 6 Females; 9 Males G2: 31 Females; 21 Males G3: 15 Females; 10 Males G4: 19 Females; 3 Males **Ethnicity** G1: African Caribbean	**Method:** Semi-structured individual interviews. Focus groups were also carried out, however, this method was not used with service users. **Length:** Not reported **Interviewer:** one of the researchers – a therapist from a BAME background **Use of interpreters:** No – participant inclusion criteria stated that they had to speak English	Thematic analysis. Content Analysis also used for focus group data.	**Themes and Subthemes reported by the paper:** - Health Beliefs and Attributions to Psychosis • Previous wrong-doing • Supernatural beliefs • Being arrested by the police (specific to only African Caribbean participants) - Help Seeking Behaviours and Pathways • African Caribbean Participants: Denial/resilience; Stigma/shame; Isolation; Mistrust and fear of mental health services; Fragmented family support; Racism; Drug misuse; Religiosity/spirituality; Previous experience of mental health services; Faith healers/traditional remedies • South Asian Muslims: Person's mental illness dealt in the family; Denial; Symptom severity/extent of illness; Stigma/shame; Community pressure/denial/community grapevine; Faith healers/imams/return to country of origin for healing/use of talisman or arm lockets with Quran verses inscribed; Religiosity; Level of education or awareness; 1st vs 2nd generation; Language/terminology; Fear of being detained

			G2: South Asian Muslims (Pakistani and Bangladeshi) G3: Majority White British G4: Mixed group			- Shame and Stigma - Opinions regarding treatment of CBT - Barriers to accessing CBT (only centred responses from therapists and lay people)
4	Weich et al. (2012)	To explore participants' accounts of recent episodes of severe mental illness and of the care that they received in a deprived, multi-cultural inner city. Additionally, to examine factors that impacted this experience and use of acute mental health services.	**Sample:** 40 service users and 13 carers. Service users had a diagnosis of a psychotic disorder. **Age:** Not reported. Inclusion criteria specified between 18-65. **Gender:** SU: 18 Females; 22 Males **Ethnicity** SU: 16 South Asians, 8 Black, 16 White Carer: 7 South Asian, 1 Black, 5 White	**Method:** In-depth interviews **Length:** between 20 minutes to 2 hours (average approx. 1 hour) **Interviewer:** 2 interviewers due to risk concerns. Interviewers were not part of the clinical team. **Use of interpreters:** Interviews largely done in English, except 2 which was conducted in Urdu (unclear whether interpreters were used)	Not clear - Coding framework developed using NVivo.	**Themes reported by the paper**: - Perspective on their difficulties - Contribution of family and friends - Experiences of acute care

5	Ally & Brennan (2015)	To explore the experiences of East African Muslim families who have a family member diagnosed with schizophrenia in the UK mental health system	**Sample:** 4 East African Muslims in London who had experience of living with or taking care of a close relative diagnosed with schizophrenia in the UK mental health system **Age:** Range: 22 – 40 years **Gender:** 2 Females, 2 Males **Ethnicity** East African	**Method:** Semi-structured interviews **Length:** Not reported **Interviewer:** Interviews by the first author. Details of interviewer not reported. **Use of interpreters:** One interview in Swahili (unclear whether interpreters were used.	Thematic Analysis	**Themes reported by the paper**: - Issues around diagnosis - Side effects and consequences of medication - Lack of choice - "Wasiwasi" – towards a more culturally sensitive mental health service provision
6	Islam, Rabiee, & Singh (2015)	To examine the cultural appropriateness, accessibility, and acceptability of the Early Intervention (EI) for Psychosis Services in Birmingham (the United Kingdom) in improving the	**Sample:** 22 service users (SU) from BAME background and was a current or past EIS user; 11 carers; 6 voluntary and community organisation representatives (V); 10 commissioners (Com); 9 EIS clinicians (Cli); and 8 spiritual care representatives (Sp) **Age:** SU: mean age 22 years	**Method:** 13 Focus Groups (6 with service users; 3 focus groups with carers; 1 with voluntary and community organization representatives; 1 with commissioners; 1 with EIS professionals; 1 with spiritual care representatives).	Thematic Analysis	**Themes and Subthemes reported by the paper:** - Help seeking • Crisis • Barriers to help-seeking • Mistrust of services - Culture and beliefs • Ambiguity and uncertainty • Knowledge and uncertainty - Social stigma and shame - Experience of EI service • User choice • Interpreters • Continuity and discontinuity of care

		experience of care and outcomes for BME patients	Carer: mean age 42 years Other groups: not collected **Gender:** SU: 11 females 11 males Carer: 8 Females, 3 Males V: 4 Females, 2 Males Com: Not collected Cli: 5 Females, 4 Males Sp: 3 Females, 5 Males **Ethnicity** SU: 9 British Pakistani, 8 Black British Caribbean, 1 British Bengali, 3 Black British African, 1 Other Carer: 3 British Pakistani, 5 Black British Caribbean, 2 Black British African, 1 Other Other groups: Not collected	**Length:** 90 minutes **Interviewer:** Interviews by first-author (accompanied by a note-taker for non-verbal interactions). Details of interviewer not reported. **Use of interpreters:** One interpreter to translate for one service user in Arabic, and the facilitator translated for one service user and two carers in Urdu.		• Treatment, support, and recovery • Withholding information - Improving BME access and experiences of services • Education and raise awareness • Meeting cultural, spiritual, religious, and individual needs • Cultural appropriateness • Collaborative working with voluntary and community organisations
7	Wagstaff, Graham, Farrell, Larkin, & Nettle (2018)	To explore the experiences of mental health services for men with a diagnosis of schizophrenia who describe their ethnic identity as ‘black’ and have	**Sample:** 7 participants with a diagnosis of Schizophrenia and a history of disengagement from mental health services **Age:** 31 – 64 years **Gender**	**Method:** Two rounds of interviews - Main interview - Clarifying interview **Length:** Not reported **Interviewer:**	IPA	**Themes and Subthemes reported by the paper:** - ‘People just keep hounding me’ - Antipathy to Medication - Choice and the value of services - Stigmatisation and identity

		a history of dis-engagement from mental health services	All males **Ethnicity** All identified as Black	Interviews were conducted by the first author. Details of interviewer not reported. **Use of interpreters:** Not reported		
8	Schofield, Kordowicz, Pennycooke, & Armstrong (2019)	To investigate Black mental health service users' perception of ethnic differences in psychosis and their explanations for these differences.	**Sample:** 35 individuals from Black African or Black Caribbean origin who have been diagnosed with a psychotic illness **Age:** Not reported **Gender:** 11 Females, 24 Males **Ethnicity** Black African or Black Caribbean	**Method**: Semi-structured focus groups **Length**: 60-90 minutes **Interviewer**: Focus group chaired by a BME former mental health service user with extensive experience working with this client group in a therapeutic environment. **Use of interpreters:** Not reported	Thematic Analysis	**Themes reported by the paper:** - Accumulation of stressors - Experience of discrimination within mental health services - Absence of community support - Stigma within the Black community
9	Lawrence, McCombie, Nikolakopoulos,	To investigate the long-term experience of living with	**Sample:** 35 individuals with first-episode psychosis.	**Method:** Individual interview **Length**:	Narrative Analysis	- Two-thirds of white British participants described attending emergency clinics at the mental health hospital voluntarily

	& Morgan (2021a)	psychosis and navigating mental health services within different ethnic groups	**Age:** 21 - 50 years **Gender:** 18 Females, 17 Males **Ethnicity** 17 Black Caribbean, 15 White British, 3 Non-British White (White Other)	Between 1 to 2 hours **Interviewer**: White male academic, already known to participants from AESOP-10 study **Use of interpreters:** Not reported		- Black Caribbean participants demonstrated a greater reluctance, and their first contact was often characterised by police involvement. Sectioning regularly followed police involvement - White British participants seemed to have greater resources for alternative care arrangements that reduced impact of everyday stressors and helped avoid or curtail admissions - **Themes reported by the paper**: • Entering mental health services • Admission to an inpatient unit • Experience of impatient wards • Positioning of medication • Attitudes towards diagnosis
10	Lawrence, McCombie, Nikolakopoulos, & Morgan (2021b)	To explore the journey through mental health services from the perspective of individuals from the black Caribbean and majority white British population to help understand variation in the use of mental health services	**Sample:** 35 individuals with first-episode psychosis. **Age:** 21 - 50 years **Gender:** 18 Females, 17 Males **Ethnicity** 17 Black Caribbean, 15 White British, 3 Non-British White (White Other)	**Method**: Individual interview **Length**: Between 1 to 2 hours **Interviewer**: White male academic, already known to participants from AESOP-10 study **Use of interpreters:** Not reported	Narrative Analysis	**Themes and Subthemes reported by the paper:** - Losing self within the system (from the account of 11 Black Caribbean, 3 White British and 1 White Other participants) • Social explanatory model • Dominance of psychiatric model • Identity as chronic patient • Self-stigma • Social/psychological causes unaddressed • Unable to break the cycle of service use - Steadying self through the system (from the account of 14 White British participants) • Biological and social model • Psychiatry served a purpose • Positive involvement in treatment decisions • Life anchored by social roles

						• Services addressing psychological needs - Finding strength beyond the system (from the account of 5 Black Caribbean women and 1 White British man) • Normal not pathological • Meaning/value in experiences • Gulf between clinical and social/psychological/spiritual framework • Alienated by the system • Sought to ground selves, address causes, change social circumstances
11	Vyas, Wood, & McPherson (2021)	To explore the stigma experiences of second-generation British South-Asian people experiencing psychosis who are using Early Intervention in Psychosis services.	**Sample:** 10 second-generation British South Asian individuals under the care of EIP **Age:** Range = 19 – 39 years, Mean = 23.5 years **Gender:** 2 Females, 8 Males **Ethnicity** All British South Asian	**Method:** Semi-structured interviews **Length**: Between 27 and 60 minutes **Interviewer**: Interviews conducted by the first author - identify as second-generation, British South-Asian women **Use of Interpreters:** Not reported	Thematic Analysis	**Themes and subthemes reported by the paper:** - The burden of silencing • "My family keeps it hush hush" • "It's a bad thing to tell people" • "It rips you from yourself" - Unrecognised aspects of their situation by services • "Understanding all these parts of me" • "It's a harsh environment" • "Services don't really see me" - Experience as "the other" • "It's contagious, it spreads" • "I'm not associated with ISIS" • "It was safer to be alone" - Finding ways to cope • "Sharing the load" • "I needed help to understand"

Table 3.

Summary of CASP Qualitative Checklist.

CASP Question	Chakraborty et al. (2009)	Penny et al. (2009)	Rathod et al. (2010)	Weich et al. (2010)	Ally & Brennan (2015)	Islam et al. (2015)	Wagstaff et al. (2018)	Schofield et al. (2019)	Lawrence et al. (2021a)	Lawrence et al. (2021b)	Vyas et al. (2021)
1. Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Partly	Yes	Partly	Yes	Partly	Yes	Yes	Yes	Yes	Yes	Yes
5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6. Has the relationship between researcher and participants been adequately considered?	Partly	No	Yes	No	No	No	Yes	No	Yes	Yes	Yes
7. Have ethical issues been taken into consideration?	Partly	Partly	Partly	Partly	No	Partly	Partly	Partly	Partly	Partly	Yes
8. Was the data analysis sufficiently rigorous?	Partly	Partly	Yes	Partly	Partly	Partly	Yes	Partly	Yes	Yes	Yes
9. Is there a clear statement of findings?	Partly	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
10. How valuable is the research?	Partly	Yes	Yes	Yes	Partly	Yes	Partly	Partly	Partly	Partly	Yes

Research Aim(s)

All eleven papers had clearly defined research aim(s) which were appropriate for qualitative research (see Table 2). Seven of the studies (see Table 2) focused only on the experiences of service users, two studies (Ally & Brennan, 2015; Penny et al.,

2009) only on the experiences of family members, and two (Islam et al., 2015; Weich et al., 2012) on the experiences of service users and carers. Therefore, the findings in this review may be heavily influenced by the experiences of service users, and may not be as reliable a representation of family members' views.

Design

All the studies justified their use of a qualitative design. Chakraborty et al. (2009), Rathod et al. (2010), Weich et al. (2010), Islam et al. (2015), Lawrence et al. (2021a) and Lawrence et al. (2021b) also recruited individuals from more than one ethnic group, enabling them to explore experiences that were similar and exclusive to each group. For the purposes of this review, the focus will mainly be on the experiences of BAME participants.

Eight of the studies (see Table 2) utilised individual interviews for data collection. Individual interviews enable researchers to collect a detailed account of participants' experiences and perceptions, making them a suitable method to address the research questions of these studies (Smith et al., 2009). Islam et al. (2015) and Schofield et al. (2019) collected data via focus groups. Schofield et al. (2019) briefly explained their reasons for using this method, whilst Islam et al. (2015) did not justify their selection. Focus groups may allow participants to build on ideas from each other, possibly challenge each other, provide valuable data, and also encourage those who may usually be reluctant to share their experiences to speak up (Barbour, 2008). However, the data collected from focus groups are often not as rich as individual interviews and may not always represent the views of each individual (Stokes & Bergin, 2006). Nevertheless, it was still an effective method to address their research aims.

Except for Chakraborty et al. (2009) and Wagstaff et al. (2018), all the studies utilised an interview schedule as a flexible guide. The structure of the schedule was at least briefly explained in Penny et al. (2009), Weich et al. (2010), Islam et al. (2015), Lawrence et al. (2021a) and Lawrence et al. (2021b), and Rathod et al. (2010) provided a list of the themes explored during interviews. By providing insight into how the guides were structured and used, a level of transparency is added, increasing the trustworthiness of these qualitative studies (Korstjens & Moser, 2018).

Sample

Except for Ally and Brennan (2015), Lawrence et al. (2021a) and Lawrence et al. (2021b), all studies used purposive sampling and explained their recruitment strategy. Purposive sampling allows researchers to selectively identify a group of individuals who meet certain criteria and can provide opinions and experiences regarding the topic of interest (Etikan et al., 2016). Although Lawrence et al. (2021a; 2021b) did not detail their recruitment strategy in their paper, it is reported that they purposively sampled participants from the ÆSOP-10 study. The details of recruitment can thus be obtained from Kirkbride and colleagues (2006). All studies reported their inclusion and exclusion criteria, increasing the transferability of the findings (Korstjens & Moser, 2018).

Except for Wagstaff et al. (2018), all studies recruited both male and female participants. The majority of studies (see Table 2) recruited Black participants (i.e. Black Caribbean and Black African). This is understandable as research shows that Black individuals may be the most impacted by the inequalities within MH services in the UK (DHSC, 2018). Approximately half of the studies (see Table 2) recruited South Asian participants (i.e. Pakistani, Bengali, Indian, Bangladeshi, and Sri Lankan). Additionally, Rathod et al. (2010) and Ally and Brennan (2015) specifically recruited Muslims. Although this takes into account the impact of intersectionality, it is unclear why Muslims were recruited specifically as the introduction of these studies considered the experiences of BAME individuals more generally. Nevertheless, considering the disparity associated with gender and ethnicity within the pathway into MH services highlighted in the introduction, it is good to see a range of demographics within the literature.

Rathod et al. (2010) excluded the data from their Chinese participants due to "insignificant numbers" and Indian participants as the researchers felt the data may have "over-extended the study" (p.514). Although this may have been done to improve homogeneity within the sample, as the researchers did not provide any information regarding the content of the data and whether it was similar or different to the themes reported, this raises question as to whether there was bias in data selection.

According to the 2011 UK census, Indians, Pakistanis, and Bangladeshis make up approximately 70% of the Asian population in the UK, whilst Chinese and individuals from other Asian backgrounds make up the other 30% (Office for National Statistics, 2011). Despite the wide variety of Asian communities that reside in the UK, it is concerning to see only South Asians represented within the literature. There is a common perception within society that East Asians and Southeast Asians do not experience discrimination due to the influence of the model minority myth (Museus & Kiang, 2009). Therefore, the lack of representation of these communities within the literature is alarming and suggests that this dangerous assumption may be perpetuated by the research community. This also questions the transferability of the findings as the voices and experiences of some individuals may currently be disregarded or under-represented, and thus whether some ethnic minority groups may have completely different experiences. As a result, it is possible that the needs of individuals from these under-represented communities are not currently being met.

In all the studies, participants had to either contact the researcher if they were interested to participate, or the researcher approached patients where only those interested agreed to participate. Although this is an ethical recruitment process, it is possible the data may be biased towards those with negative experiences who wanted to get their perceptions across, whilst those with positive experiences may not have seen a benefit to participating.

The number of participants in the studies range from 4 to 53 (Mean = 22.3, SD = 15.9). Smith et al. (2009) recommend a smaller sample for IPA as it allows for a more detailed interpretation of people's experiences. Penny et al. (2009) and Wagstaff et al. (2018) recruited seven and eleven participants respectively, falling within their recommendations. For Thematic Analysis, although Braun and Clarke (2006) suggest smaller sample sizes may be appropriate to allow for a detailed analysis, Fugard and Potts (2015) highlight that the current literature suggests a wide range of sample sizes recommendations, ranging from two to several hundreds, suggesting no clear recommendation for what is optimal. Similarly, there does not seem to be a recommended sample size for narrative analysis. Nevertheless, some argue that sample size is not as important as saturation of data (Fusch & Ness, 2015). Saturation of data in qualitative research refers to the point where obtaining more data would not add new information. Only Rathod et al. (2010) and Weich et al. (2010) explicitly mention how saturation of data was reached, whilst other studies did not consider this. Therefore, is it unclear how the authors in these studies determined their sample size and whether it was appropriate.

Except for Vyas et al. (2021), all of the studies did not mention how they cared for participants' wellbeing, raising ethical concerns. Speaking in detail about personal and at times difficult experiences could have caused distress for participants (Smith et al., 2009). In Vyas et al. (2021) this was briefly acknowledged by reporting that participants were debriefed after the interview, with no detail on whether this included a check on participant's wellbeing.

Researcher's Position

In qualitative research, it is important for researchers to reflect on and acknowledge their own possible bias and assumptions throughout all stages of the research (Korstjens, & Moser, 2018). This is because data collection and analysis are heavily influenced by the researcher, such as what questions are asked in the interview or what themes are reported. Penny et al. (2009), Weich et al. (2010), Ally and Brennan (2015), Islam et al. (2015), and Schofield et al. (2019) did not mention any consideration or acknowledgement of the researcher's position and influence on any stages of the research.

Chakraborty et al. (2009) briefly acknowledged the researcher's ethnicity may have influenced participants' responses in the interview. However, there was no acknowledgment of how the researcher's ethnicity may have influenced the questions asked, especially as they did not utilise an interview schedule, increasing the risk of bias. There were also no reflections on how the researcher's own identity and assumptions may have influenced the design of the study or the data analysis.

Several strategies were used by the other studies to address the researcher's position and reduce bias where possible, including the use of reflective diaries (Lawrence et al., 2021b; Wagstaff et al., 2018), bracketing interviews (Rathod et al., 2010), supervision (Rathod et al., 2010; Wagstaff et al., 2018), discussions with research team about positions and identities (Lawrence et al., 2021a; 2021b), clarifying data with participants (Vyas et al., 2021; Wagstaff et al., 2018) and triangulation or audit (explained below).

Rathod et al. (2010) and Vyas et al. (2021) also acknowledged the possible impact of the shared ethnicity between the researcher and the participants, and the possible benefits of this such as creating a sense of sameness and safety during interviews. However, the researcher’s ethnicity may have also increased the risk of observer effect as participants may have spoken only about experiences they believed the researcher wanted to hear about (Tetnowski, 2015). Lawrence et al. (2021b) acknowledged the impact of two of the authors’ previous research experience on their awareness of the limitations of the medical model during data interpretation. However, overall, most of the studies only refer to these strategies briefly and do not describe the positions the researchers have taken, therefore not providing readers with a level of transparency that could help them understand the data collection and interpretation process.

Analysis

The most common analysis method used was Thematic Analysis (see Table 2), whilst Penny et al. (2009) and Wagstaff et al. (2018) analysed their data using IPA, and Lawrence et al. (2021a; 2021b) used Narrative Analysis. All these methods were appropriate considering the research aims of these studies.

It was unclear what analysis method was used by Chakraborty et al. (2009) and Weich et al. (2010). Chakraborty et al. (2009) reported using a qualitative software called QSR NUD*IST-4 to analyse the interviews, whilst Weich et al. (2010) reported that a coding framework was developed using the software NVivo. However, it is unclear what qualitative method or qualitative analysis was used in these studies.

Although this software enables researchers to group interview data into categories or codes, the data could be interpreted and presented differently depending on the qualitative method or analysis chosen. Hence, it is important for the researchers to have included this information. Nevertheless, Weich et al. (2010) presented quotes to illustrate the themes, providing readers with some sense of how data were interpreted. For Chakraborty et al. (2009), the quotes were not presented according to the coding categories and subcategories developed, making it unclear how those categories were derived.

Rathod et al. (2010), Weich et al. (2010), Schofield et al. (2019), Lawrence et al. (2021a; 2021b) and Vyas et al. (2021) used additional coder(s) who independently analysed a sample of the transcripts, and compared the themes constructed. This process is called “investigator triangulation” and is an effective method to increase the validity and quality of qualitative analysis (Guion et al., 2011, p.1). Additionally, as studies Rathod et al. (2010), Weich et al. (2010), and Islam et al. (2015) interviewed individuals from several groups and illustrated all groups representing each theme, the “data triangulation” in these studies increased their validity (Guion et al., 2011, p.1). In Penny et al. (2009), Islam et al. (2015), Wagstaff et al. (2018), and Schofield et al. (2019), the coding process completed by the first author was discussed and/or reviewed by other member(s) of the research team, described as an audit.

Although not all the studies used triangulation or audit as a method to increase validity, all the studies (except Chakraborty et al., 2009) provided examples of quotes to illustrate each theme. Hence, the readers can decide for themselves whether the themes are valid according to the data collected. Although the reader does not have access to all the data and the quotes presented are carefully selected, it still does provide some credibility and confirmability to the findings (Korstjens & Moser, 2018).

Key Findings

Following the thematic synthesis, six themes were derived from the papers. To maintain transparency and rigour, a matrix illustrating the synthesis process (example quotes, codes, and themes) is presented in Appendix A. Due to the studies being of largely similar quality, and the consistency in themes across papers, the quality of the studies will not be referred to in this section.

Alternative Explanations of Psychosis that did not Conform to the Western Medical Model

The studies highlight the different ways in which individuals from BAME communities and their families explain and understand their difficulties which do not conform to the traditional Western medical model of psychosis. Alternative explanations cited included religious or supernatural causes, social stressors, loneliness or lack of support, and being misunderstood or stereotyped. Participants also highlighted how experiences that would be considered usual occurrences in their respective culture (e.g. having visions in Caribbean or African Culture) could be seen as abnormal and labelled as psychosis within the UK community (e.g Schofield et al., 2019).

Social stressors, especially the additional struggles faced by BAME individuals, appeared to be one of the most common explanations cited. For example, a participant in Schofield et al. (2019) highlighted:

> “the ethnic minority experience is not the same as the native experience. Maybe we’ve had more struggles in life, and especially inner city and stuff like that, and

basically the struggles that we have in life could turn us in a different direction" (p.967).

Moreover, as another form of social stress, participants in Vyas et al. (2021) highlighted difficulties in navigating their identities (i.e. British and Asian) and adapting to their environment. For example, Anwar expressed that "if you're trying to adapt to different cultures and you're doing it so much on the fly that you start to question your own beliefs, is this my belief or is this someone else's belief that I'm taking in", and Tippu reflected that "they just want keep the White, English people. I'm the one that's always been targeted. I'm fed up of this country, I don't belong here" (p.6). Participants also emphasised the pressure to distance themselves from their South-Asian culture in order to adapt to their environment as a result of these incongruences.

The Rigidity of The Medical Model Used Within MH Services

The rigidity of the medical model used within MH services in the UK was also highlighted. Participants reflected on their dissatisfaction on how the diagnosis was given and explained to them, and many refuted the labels as an accurate reflection of their experiences. Receiving a diagnosis was also described as "something that was done to them" instead of it being a collaborative process between professionals and the individual (Lawrence et al., 2021a, p.4)

Some family members also expressed frustrations at the diagnosis process, reflecting that it was a "trial and error" approach (Ally & Brennan, 2015, p.47), resulting in uncertainty around the validity of the diagnosis and trust in professionals' decisions. Moreover, as highlighted in Penny et al. (2009), "none of the participants used the terms psychosis or schizophrenia at all in the interviews" (p.977), suggesting these diagnoses may not be fully accepted by participants and their families.

This dissatisfaction with the medical model was also further exacerbated by professionals' and the system's unwillingness to consider cultural explanations of distress and psychosis, leaving many participants feeling misunderstood and not listened to. Participants described psychiatry services as being "sterile" (Lawrence et al., 2021a, p.5) and medication focused. Participants in Islam et al. (2015) and Lawrence et al. (2021a) highlighted this may be due to the cultural differences between them and western professionals, citing "we can't blame them because they're upbringing is like westernized, they can't understand if we talk about Jinns" (Islam et al., 2015, p.747).

Participants also highlighted that professionals' lack of cultural awareness and willingness to understand can be harmful and lead to misdiagnosis or pathologisation of experiences. For example, Lawrence et al. (2021a) highlighted:

> "for many participants, their diagnosis represented a label that they considered to be inadequate, an oversimplification for the benefit of others. As Tessa (BC) explained, 'I was immediately labelled, I didn't feel as though they took their time out to address any of my problems they were all just take, take, take'" (p.4).

The impact of a diagnosis was highlighted in Lawrence et al. (2021b), stating that individuals expressed "tension between accepting diagnoses and the need for treatment, and deeper beliefs that 'schizophrenia' and 'psychosis' signified madness" (p.4), suggesting that being given these diagnoses could result in someone questioning their own sanity and identity, especially as "if you're told enough times you believe it" (p.6). Additionally, a participant also highlighted that their diagnosis influenced the way their behaviours were interpreted and perceived by professionals around them.

Medication vs Psychological Therapy

A common theme in all the studies was the forceful use of medication and its negative side effects, and often compared to the lack of psychological input offered. Medication was described as something that was given "against her will" (Chakraborty et al., 2009, p.24), "necessary evil" (Weich et al., 2010, p.122), and "prescribed inappropriately, and under duress" (Schofield et al., 2019, p.969). Although previous literature suggests that BAME individuals are more likely to be prescribed antipsychotic medication, there was a difference in opinion within the studies in this review. Rathod et al. (2010) highlighted that medication was "overused in BME patients" (p.522) whilst a participant in Schofield et al. (2019) highlighted, "I have never seen any situation: 'this is for Black people this is for white people'. The medication is all the same" (p.969).

The negative side effects of medication were commonly cited as being "worse than schizophrenia itself" (Ally & Brennan, 2015, p.47), and were often cited as a reason for service dissatisfaction and disengagement. For example, a family member in Ally and Brennan (2015) highlighted:

> "now he has heart problems; before he did not have rolled up eyes, but now he is having it every time […] Whenever he goes to the hospital and tells them that he does not feel good […] they give him even more medication than before […] they may give four to five drugs all to do with hearing voices […] now he cannot really do anything for himself" (p.47).

Service users and their families often reflected on feeling dismissed and not listened to when concerns around medication were highlighted. As a result, some reported stopping medication without consulting professionals, sometimes leading to "worsening of symptoms and repeat hospital admissions" (Lawrence et al., 2021a, p.4). Lawrence et al. (2021a) also highlighted that participants who adhered to taking their medication regularly reported engagement with professionals who were "sympathetic to the negative effects of medication" (p.4), suggesting that professionals' attitudes play a big role in the way medication may be perceived and tolerated. This is also especially important as many participants reported not being given enough information about their medication and the reasons for it being prescribed, impacting their attitudes towards it.

Participants also expressed their preference for talking therapy over medication. For example, Ally and Brennan (2015) highlighted, "they expressed frustration with the process of diagnosis and treatment, which was, in all cases, medication, with no 'talking therapy' offered" (p.47), and one family member expressed "if they could get him [her husband] talking therapy, it could be more effective than the psychiatric medication" (p.48). Participants in Rathod et al. (2010) and Schofield et al. (2019) suggest that BAME individuals are less likely to be offered psychological input due to their ethnicity. According to Vyas et al. (2021), "those who felt overlooked by services […] reported not having been offered psychological input" (p.8).

Lack of Autonomy, Choice, and Individuality

Participants often reflected on the lack of autonomy and choice in relation to diagnosis and medication. Furthermore, narratives around coercion and lack of choice over treatment pathways and service accessed were highlighted, and participants reflected on the dehumanising impact of this. For example, Rathod et al. (2010) highlighted that "a common theme by a majority of BME patients was that of being treated impersonally, as 'a number'" (p.524), and Ally and Brennan (2015) highlighted "the treatment he is receiving from psychiatry honestly speaking I would like to stop it […] All they do is trying things but they cannot do that to humans" (p.48). Additionally, a participant in Chakraborty et al. (2009) captured the coercive nature of some services in their quote "she's not gonna do what we say, so we're gonna hold her down" (p.24) when describing professionals' attitude.

Although this review is focused on the experiences of BAME service users, it is also interesting that stories illustrating a sense of control or ability to negotiate care was only expressed by White British participants. For example, Lawrence et al. (2021a) highlighted "it was notable that a handful of white British participants recounted success in negotiating this aspect of their care with some arguing that a reduced dosage was necessary to continue their undergraduate degrees or careers" (p.4) and that "two-thirds of white British participants described attending emergency clinics at the mental health hospital voluntarily" (p.3).

Due the lack of autonomy and choice, many participants described a sense of resignation and acceptance over their situation. For example, a participant in Wagstaff et al. (2018) expressed "well it's not my choice you know. I ain't got a choice because I got, if the MH people come with me or come to give me medication, I take it, you know what I mean? But deep down I really don't want it" (p.162), illustrating the hopelessness and disempowerment associated with being a service user. Similar experiences and feelings were also echoed by family members such as in Ally and Brennan (2015): "They do not give us a choice whether we want him to take the medication or not. You can ask them questions but you cannot tell them what to do. I think it is because they are in much more control" (p.48).

Stigma within Services and Society

The stigma around MH within Asian and African communities was also highlighted. There was a sense of "family honour" (Rathod et al., 2010, p.520) and "family pride" (Vyas et al., 2021, p.5) being an important aspect of Asian communities that needed to be protected, and that MH difficulties would destroy it. Within African communities, there seemed to be the perception that individuals with MH difficulties would not be "understood" (Islam et al. 2015, p.745) and it will be "hard to accept" (Schofield et al. 2019, p.970). Members of both cultures expressed worries around being judged and being perceived as "crazy" (Vyas et al., 2021, p.5). Service users also highlighted the stigma associated with being involved with MH services, which can further isolate them from their communities. For example, Wagstaff et al. (2018) highlighted that "they recognized that involvement with mental health services carried social stigma, which negatively impacted upon them" (p.162).

Support and Resources Required for Recovery

Various types of support were highlighted as being helpful or as something that would be helpful if implemented. For many individuals and their families, their faith and faith-based treatments provided a sense of support and hope. For example, family members in Penny et al. (2009) explained that "when we went there [Pakistan], the molvi at the mosque whispered some things on the water which was given to him. He was really happy and very calm with that" (p.979). Considering the importance of faith in service users' and their families' lives and recovery journey, participants also suggested that professionals in MH services should work collaboratively with faith scholars. For example, a participant in Ally and Brennan (2015) expressed that "it should be arranged for the [Muslim] scholar and the psychiatrist to sit together and try to find a solution because they both help, so they might be able to find the cure" (p.49).

There was also the perception that BAME individuals have less resources than White British individuals, as highlighted by the following quote from Schofield et al. (2019):

> “the biggest factor in this country, why most Black people are diagnosed, it is isolation because where we come from, massive families, with good friends, got relatives, we’ve aunties. But when you come here to this country you are alone in your house” (p.969).

As highlighted by Penny et al. (2009), Weich et al. (2010), and Ally and Brennan (2015), family members play a significant role in service users’ journey to recovery. For example, Penny et al. (2009) highlighted that “the family was felt to be primarily responsible for the welfare of the young person” (p.980). Despite this importance, Ally and Brennan (2015) highlighted how family members did not feel like they had a voice in the system and often felt dismissed.

Discussion

This systematic review aimed to explore qualitative reports of BAME individuals’ and their families’ experience of psychosis in the UK. This review aimed to understand the factors that impact people’s experiences, and barriers to access and engagement with MH services. Eleven qualitative studies were identified to address these aims, and six common themes were derived from these studies.

The most common explanation for psychosis reported by participants was social stressors. As highlighted in the introduction, the experiences of being from a BAME community in the UK may involve experiences of discrimination, vulnerability, and alienation, which may increase the risk of developing MH difficulties such as psychosis (Boydell et al., 2001; Karlsen et al., 2005; Van Os et al., 1996). This is further supported by the Traumagenic Neurodevelopmental Model of Psychosis (Read et al., 2001; Read et al., 2014), which suggests that these stressors may produce vulnerabilities that increase one's risk of having experiences associated with a psychosis diagnosis.

Despite the increase in social stressors and risk, the findings also highlight the lack of resources reported by BAME service users, especially around isolation as a result of migration and stigma. Furthermore, as highlighted by CRT, racism and inequalities are embedded across all aspects of society (Moodley et al., 2017). For example, Byrne et al. (2020) highlight racial inequalities across various domains in the UK such as healthcare, education, housing, and employment. Therefore, although not highlighted by the findings, this review predicts that the lack of resources faced by BAME individuals may be more acute and should be further investigated.

Majority of the studies also highlighted the different ways in which individuals from BAME communities and their families explain and understand their difficulties which do not conform to the traditional Western medical model of psychosis. Participants highlighted how differences in culture, beliefs and explanations could lead to misunderstandings and common cultural behaviours such as having visions being labelled as symptoms of psychosis, resulting in a diagnosis of psychosis or schizophrenia. Most of the participants described this diagnostic label as an inaccurate representation of their experiences and found this process distressing. This is in line with previous studies suggesting that psychosis symptoms such as hearing voices may be perceived as a positive experience in some cultures (e.g. Luhrmann at al., 2015), and that individuals with positive experiences of hearing voices are more likely to cope well and report less distress (Ludici et al., 2019; Romme & Escher, 1989). Additionally, society's response to individuals' experiences of psychosis may be the cause of distress and impact one's ability to cope, and not necessarily the experiences of hearing voices itself (Clements et al., 2020).

In addition to explanations and diagnosis, findings also highlighted the coercive nature and rigidity of treatment pathways, especially in relation to medication. National Institute for Health Care and Excellence (NICE) guidelines (2014) recommend that information about medication should be provided to service users, including possible benefits and side effects, and that the choice of medication should be made collaboratively between the service user and clinician, and where appropriate with the involvement of the carer. However, this was not the reported experience of participants in the studies reviewed, highlighting areas for concern. According to Kane and colleagues (2013), some of the factors that impact medical adherence include lack of information about medication, perceived risks and benefits, past experiences with the medication, side effects, and therapeutic alliance. Therefore, the coercive use of medication and lack of information, may not only be impacting service users' engagement with services, but may also be reducing medication adherence, and as a result its effectiveness. Moreover, as theorised by Keating and Robertson (2004), this may also be perpetuating the "circle of fear", maintaining service user's mistrust of MH services.

NICE guidelines (2014) also recommend a combination of medication with psychological therapy. However, many participants reported a lack of psychological therapy offered. This is concerning as the efficacy of antipsychotic medication long term is still being explored. For example, a 20-year longitudinal study by Harrow and colleagues (2014) found that the use of antipsychotics did not reduce the severity or frequency of psychotic symptoms long-term. This combined with the possible debilitating side effects reported by many participants in the studies reviewed, raises questions regarding the benefits of antipsychotics. Additionally, research on voice hearers found that the opportunity to understand, accept and makes sense of one's experiences was reported to be the most helpful aspect of one's recovery journey (e.g. Beavan, 2011; Clements et al., 2020), further highlighting the importance of psychological support.

Moreover, it was speculated that the lack of psychological therapy offered was particular to BAME service users. This is supported by a survey of over 10,000 individuals with a diagnosis of schizophrenia, which found that BAME service users were less likely to be offered cognitive behavioural therapy for psychosis as compared to White British service uses (Das-Munshi et al., 2018). The disparity in accessing and choosing treatment between BAME and White service users is further highlighted by Lawrence et al (2021a). They found that White British participants reported having more power in negotiating their treatment pathway and more likely to be accessing services voluntarily. This supports the ideas proposed by CRT (Moodley et al., 2017), suggesting that there are systemic prejudices that are impacting the care offered and received by individuals from BAME communities.

Strengths and Limitations

A strength of this study is that the themes were relatively similar across the studies, suggesting that the findings may be reliable, despite the different limitations of each study. Additionally, this review has followed a specified method as outlined by Thomas and Harden (2008). The transparency of the process enables readers to make their own interpretations and identify any possible bias (Korstjens & Moser, 2018).

However, as previously highlighted, the studies in this review only highlight the experiences of individuals from Black and South Asian communities, questioning whether the findings are a representative of all BAME communities' experiences. Moreover, the use of the term 'psychosis' may be considered a limitation of this study as it perpetuates the medical model and the discourse that experiences characterised as 'symptoms of psychosis' are a sign of an illness or deficit (Boyle, 2011). However, as this is the term used widely within the literature, it was necessary to use this term to locate appropriate studies and represent the findings accurately.

Clinical Implications

The negative account of individuals experiences highlighted in this review is not intended to place blame or fault within professionals or services, but instead to highlight ways in which support, care, and patient satisfaction can be improved, in line with NHS values.

MH services could consider introducing some flexibility within the medical model. For example, giving individuals the space to bring their cultural understanding and perceptions of their difficulties, and collaboratively developing a formulation to help people understand their experiences could promote service users' management of their difficulties, positive self-concept and sense of control (Jackson et al., 2010; Ludici et al., 2019).

Professionals should also consider the impact a diagnosis may have on an individual, and service users and their families should be able to explore the pros and cons of being given a diagnosis before making a decision (Vyas et al., 2021). This is important as language used can impact an individual's perception of their experiences (Ludici et al., 2019). Hence, diagnostic language which may be interpreted as a sign of being sick or crazy (as illustrated in the findings of this study) may not be helpful in promoting sense of control and agency (Romme & Escher, 1989). To aid this process, professionals could consider working collaboratively with faith scholars to improve their understanding and awareness of cultural norms and explanations, whilst also working towards normalising MH difficulties within these communities and reducing stigma.

MH services should also reflect on the current coercive practices that was highlighted in this review. As recommended by the NICE guidelines (2014), steps should be taken to ensure service users and their families have a voice in deciding the most suitable treatment pathway for them. Professionals should also introduce medication in a more collaborative way, explaining the reason for the medication being prescribed, the possible side effects on taking it, and take into account individuals' concerns. Moreover, the possible risk of harm from medication should be considered, and professionals should explore alternative medication and lower doses wherever possible. Ultimately, medication should not be forced upon individuals as they have a right to make an informed decision if there are no substantive risks to themselves or others involved, even if professionals may deem it as an unwise decision (Mental Capacity Act, 2005).

Moreover, a preference for talking therapy was highlighted to support individuals to understand their experiences. Hence, even where medication is agreed to be a suitable therapy, service users should also be given the option to engage with psychological support (NICE, 2014). Services should also ensure they are not unconsciously discriminating against certain groups of individuals, and could consider carrying out a service evaluation to assess whether psychological support is being offered to and accessed equally by all groups.

As highlighted above, family members play an important role in service users' life, and their support is greatly valued. Therefore, as recommended by NICE guidelines (2014), services should provide the option for service users to involve their families. When families are involved, they should also be given the space to voice their understandings and concerns without being dismissed.

Research Implications

Most notably, the current literature is lacking in diversity. Hence, future research should aim to recruit participants from various BAME backgrounds, especially those from East Asian backgrounds. Moreover, only four out of the eleven studies explored the experiences of family members, highlighting the need for more research in this area. Furthermore, research on services implementing the suggestions related to clinical practice that was highlighted above, and the perceived impact as reported by service user and their families would be beneficial. Additionally, Vyas et al. (2021) briefly highlighted the difficulties BAME individuals may face in navigating competing cultures and explanations. However, this was not explored in the other studies, providing room for further research in this area.

Conclusion

This review aimed to evaluate qualitative reports of BAME individuals' and their families' experience of psychosis in the UK, as a way to further understand the factors that impact their experiences and what barriers may be currently impacting access and engagement with MH services in the UK. The findings highlight several themes illustrating current practices that may be acting as barriers to patient satisfaction and engagement such as lack of cultural understanding, rigidity of the medical model, forceful medication and its side effects, lack of autonomy, choice and individuality, stigma, and lack of support and resources. The review also reveals the scarcity of research in this field, prompting the need for further research to be conducted.

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Section B: Empirical Paper

Hearing Voices within a Western Society from an Ethnic Minority Perspective: Navigating Explanations and Culture

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Abstract

Introduction: Research suggests the process of navigating multiple explanations of hearing voices and cultural identities may impact ethnic minority individuals' experiences of hearing voices.

Aim: To explore ethnic minority voice-hearers' experiences of being immersed within and navigating UK Western society and explanations of hearing voices.

Method: Data was collected via semi-structured interviews and identifying stories from published books. The four interviews and eight stories were analysed using Reflexive Thematic Analysis.

Results: Six themes were developed: the individuality of hearing voices explanations, clash of cultural identities, challenges of hearing voices within current society, labels – forceful and powerful, real choice vs. illusion of choice, and recovery is a continuous process.

Discussion: The findings highlight the importance of considering ethnic minority voice-hearers' understanding and meanings of their experiences, complexities of navigating cultural identities, influence of stigma and discrimination, possible retraumatisation, and elements of recovery. Limitations of the study, research recommendations, and clinical implications are also discussed.

Keywords: Hearing Voices, Culture, Ethnic Minority, Qualitative, UK

Introduction

De-medicalising Hearing Voices

In Western societies, the psychiatric medical model is the predominant model used to understand and explain mental health (MH) difficulties (Fernando, 2011). Within this model, the experience of hearing voices (HV) is often considered a key symptom of several MH disorders, including schizophrenia and/or psychosis (McCarthy-Jones, 2012). Boyle (2011, p.29) argues that this unhelpfully categorises people who hear voices as “abnormal”, “defective” or having “deficits”. However, McCarthy-Jones (2012) explains “voices are not a characteristic symptom of schizophrenia because they are common in patients with this diagnosis; they are common as the DSM defines hearing voices (and particularly certain types) as a characteristic symptom of schizophrenia” (p. 102).

Boyle (2011) describes this process in psychiatry where human distress and experiences are labelled as symptoms, disorders or illness, as an unconscious avoidance of context. However, people’s context, which include past experiences, social circumstances, and environment, are important factors which impact current experiences and distress (Boyle, 2011; Read et al., 2014). Boyle (2011) and Davies (2021) suggest that the avoidance of context may be driven by the threat it poses to Western pervasive neoliberal ideologies about individuals having autonomy and being largely responsible for their circumstances and fate. Whilst this ideology emphasises individual freedom, arguably it may also reduce the government’s sense of obligation to support those in need.

Moreover, the framing of HV as a symptom of an impairment or illness may foster stigma against voice-hearers (Vilhauer, 2016). A review by Beavan and colleagues (2011) estimates five to fifteen percent of adults within the general population hear voices. The difference between voice-hearers with and without a psychiatric diagnosis may be attributed to the distress experienced due to HV (Romme & Escher, 2000), and some of this distress may be attributed to the negative connotations ascribed to HV (Clements et al., 2020; Vilhauer, 2016).

The current study focuses on experiences of HV specifically and disagrees with the use of the label 'psychosis' to define this experience. However, due to the pervasive use of this label within existing literature, this term will be used when referring to findings from existing research.

Non-Western Explanations of HV

Research suggests there are many explanatory models for psychosis experiences such as HV, and that explanations within ethnic minority communities in the UK often revolve around culture, society, or spirituality (e.g Bhikha & colleagues, 2015; McCabe & Priebe, 2004). These findings are echoed by research from different countries (e.g. Abbo et al., 2008; Mirza et al., 2019; Razali et al., 1996). Taylor and Murray (2012) found that their participants' spiritual explanation of their voices resulted in a perceived reduction in distress, provided a sense of control over their experiences, and increased a sense of purpose in their lives, illustrating the possible benefits of alternative HV explanations.

The intention of this study is not to suggest that one type of HV explanation is better than another, as a range of explanations may have the potential to increase distress. For example, Gureje and colleagues (2006) found that those with religious and/or magical causal explanations of MH difficulties were more likely to have negative and stigmatising perceptions of them, suggesting cultural explanations could cause distress when influenced by stigma. Hence, it is instead about acknowledging that people may have different ways of understanding and making sense of their experiences, and that culture may act as a framework which helps people make sense of their voices (Larsen, 2008).

The Context of HV as an Ethnic Minority in the UK

Culture is defined as “a flexible system of values and worldviews that people live by, a system by which we may define aspects of our identities and negotiate our lives” (Fernando 2012, p.113). Ethnicity is the way individuals define and perceive themselves in relation to their culture (Fernando, 2011).

Although research focusing on differences between cultures or ethnicities could perpetuate discourses around otherness (Dalal, 2002), culture and ethnicity are important aspects of people’s context (Boyle, 2011). In the UK, the social context of ethnic minority individuals (i.e. not White British) often differs from those in the majority group due to ethnic inequalities within education, housing, employment, and access to healthcare (Byrne et al., 2020).

Research on Ethnic Minority Voice-Hearers’ Experiences in the UK

Research shows that individuals from ethnic minority groups in the UK are more likely to be diagnosed with psychosis, be detained under the MH Act, experience coercive treatment pathways, and are less likely to be offered psychological therapy (e.g. Boydell et al., 2001; Halvorsrud et al., 2018; Halvorsrud et al., 2019; Mann et al., 2014; Morgan et al., 2018). This is often discussed in the context of institutionalised racism, which proposes that MH services may be unconsciously perpetuating discriminatory practices (McKenzie & Bhui, 2007; Nazroo et al., 2020).

Karlsen and colleagues (2005), for example, found that ethnic minority individuals had an increased risk of experiencing symptoms associated with psychosis, and suggested that this increase may be related to experiences of direct and perceived racism. Moreover, Boydell and colleagues (2001) found that the rate of ethnic minority individuals receiving a psychosis diagnosis was higher for those in predominantly white areas, and suggests that this may be associated with higher incidences of discrimination and racism in less diverse areas. These findings are also supported by the Traumagenic Neurodevelopment Model of Psychosis, which suggests that experiences of childhood adversities, including experiences of racism, may increase one's vulnerabilities to changes in the brain and heightened stress sensitivity, which may be associated with an increased risk of 'psychosis' experiences (Read et al., 2001; Read et al., 2014). Therefore, ethnic minority individuals' experiences of discrimination and racism may be increasing their risk of developing symptoms associated with a psychosis diagnosis.

Moreover, qualitative studies exploring the experiences of ethnic minority individuals with a psychosis diagnosis also highlight the rigidity of the medical model which does not consider cultural explanations and understandings, leaving service users feeling misunderstood, labelled against their will, and feeling misdiagnosed (e.g. Chakraborty et al., 2009; Islam et al., 2015; Lawrence et al., 2021a; 2021b; Penny et al., 2009; Rathod et al., 2010; Schofield et al., 2019; Weich et al., 2010). Moreover, Vyas et al. (2021) found that second-generation British South Asian participants also experienced difficulties in navigating the various aspects of their identities (e.g. British versus South Asian), which they perceived impacted their experiences of psychosis.

Possible Influence of Cultural Identities on HV

Similar to Vyas et al. (2021), Rousseau and colleagues (2005) found that for second-generation adolescent immigrants in Canada, having conflicting HV explanations (native culture versus current culture) increased distress, confusion and incongruence. This suggests that navigating cultural identities and explanations may have an influence on HV experiences.

Social Identity Theory posits that social identity is “that part of an individual’s self-concept which derives from his knowledge of his [sic] membership of a social group (or groups)” (Tajfel, 1978, p.63). Bhugra (2004) speculates that the process of bringing two cultures, and thus two social identities, together and navigating the differences and changes to one’s identity, which they termed as “acculturation” (p.134), may contribute to increased distress, impact one’s self-esteem, and contribute to the development of psychological difficulties. Bhugra (2004) added that for individuals who are in the minority within their environment, the feelings of alienation and dissonance in identities may be even higher.

Goffman (1963) further suggests that stigma is a reaction from others that results from certain attributes associated with specific social identities being discredited or deemed as undesirable by others. Considering the impact of racism and how HV may be perceived within society, ethnic minority voice-hearers may face double the stigma. These reactions from others consequently taint one’s perception of one’s own identity and could create a sense of not belonging (Goffman, 1963; Corrigan, 2008), which could negatively impact one’s perception of self (Leary et al., 1995; Corrigan, 2008).

Aims And Research Questions

The National Health Service (NHS) holds values around “respect and dignity”, and “everybody counts” (Department of Health and Social Care [DHSC], 2021, para.16-20), emphasising the importance of respecting and acknowledging the influence of culture and identities.

Previous research has focused on exploring ethnic variations in how individuals explain experiences of psychosis, and/or their experiences of society and services. However, research has not explored how ethnic minority voice-hearers specifically navigate having multiple explanations whilst being immersed within a Western UK society. Moreover, research has not explicitly explored the possible influences of navigating cultural identities on HV experiences. It is important to explore this context further, as the avoidance of such exploration would instead maintain power imbalances within society and "protect relatively powerful groups from scrutiny" (Boyle, 2011, p. 39).

Therefore, the aim of this study was to explore ethnic minority voice-hearers' experiences of being immersed within and navigating Western society and explanations of HV in the UK. This study proposed the following research questions to guide the inquiry, but without any expectation that only these specific questions would capture participants' views. In this sense, the aim was not to provide an answer for each of these questions:

a) How do participants navigate having multiple cultural identities and HV explanations within UK society?
b) What is the perceived impact, if any, of having multiple identities and explanations on participants' HV experiences?
c) What is the perceived impact, if any, of having different identities and explanations in relation to experiences with MH services?

Method

Design

This qualitative study adopted a critical realist epistemology. Critical realism provides "a position that retains a concept of truth and reality but recognises that human practices always shape how we experience and know this" (Braun & Clarke, 2022, p.169). This approach allows the researcher to consider participants' perspectives and experiences of HV.

Individual semi-structured interviews and stories from published books were analysed using reflexive thematic analysis. An inductive method was chosen as it allows the development of themes driven by the data (Braun & Clarke, 2022).

Reflexive thematic analysis was chosen as this method allows a combination of in-depth interview data and prior existing data and appears to be the most appropriate for this study (Braun & Clarke, 2022). As homogeneity of the sample could not be guaranteed with the stories from the published book, it would not have been appropriate to utilise interpretative phenomenological analysis (Smith et al., 2009). Additionally, as the author of this research did not have any control or awareness of the questions asked to the storytellers, and it is unclear whether the stories had been edited in any way by the authors of the book or how the narratives were created, using narrative analysis may have also not been appropriate (Earthy & Cronin, 2008).

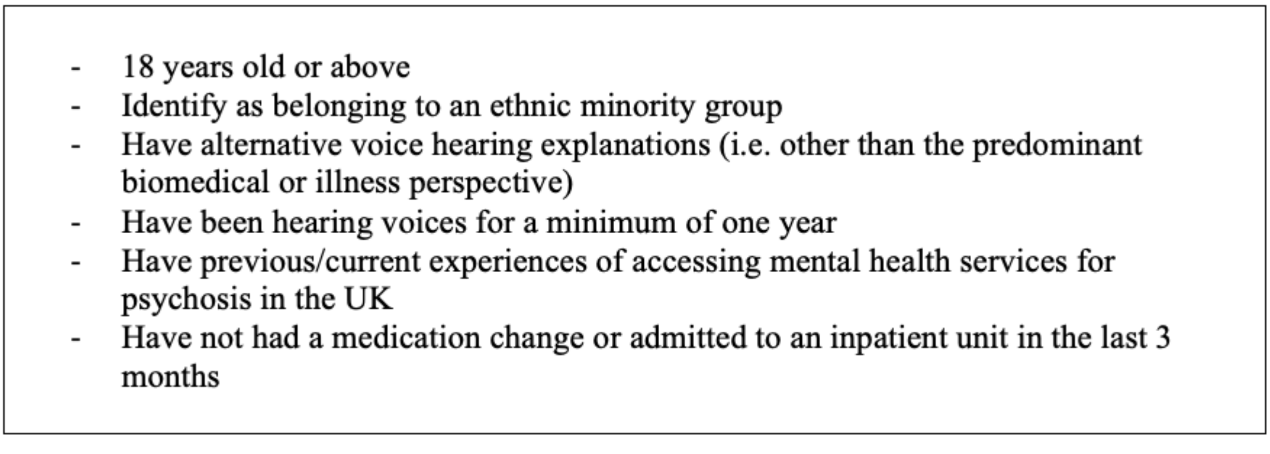
Data

Participants

Participants were recruited via opportunity sampling. The research was advertised on social media platforms and non-NHS organisations (Appendix C-D). Individuals who were interested contacted the researcher directly to participate. Figure 1 describes the participant inclusion criteria. Participants were given a £10 Amazon voucher for their participation.

Figure 1.

Participant inclusion criteria.

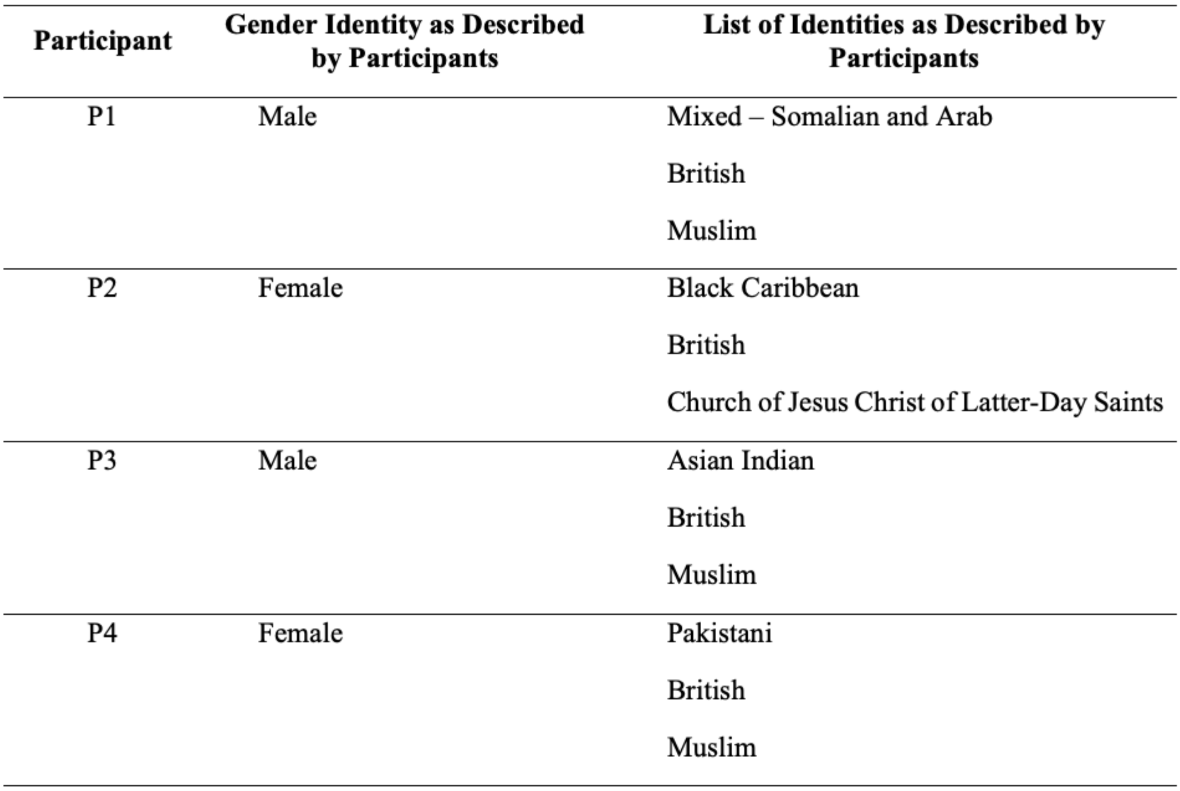


- 18 years old or above
- Identify as belonging to an ethnic minority group
- Have alternative voice hearing explanations (i.e. other than the predominant biomedical or illness perspective)
- Have been hearing voices for a minimum of one year
- Have previous/current experiences of accessing mental health services for psychosis in the UK
- Have not had a medication change or admitted to an inpatient unit in the last 3 months

Five individuals were recruited to participate in an interview. However, one participant dropped out due to an emergency. After a follow-up telephone conversation, the author and participant decided that they were too distressed to safely participate at a later date. In total, four participants were interviewed. Participants comprised two males and two females, aged between 35 and 59 years (*M* = 41.8, *SD* = 11.5). Table 1 illustrates participants' identities.

Table 1.

Participants' description of their identities



Participant	Gender Identity as Described by Participants	List of Identities as Described by Participants
P1	Male	Mixed – Somalian and Arab British Muslim
P2	Female	Black Caribbean British Church of Jesus Christ of Latter-Day Saints
P3	Male	Asian Indian British Muslim
P4	Female	Pakistani British Muslim

Stories from Published Books

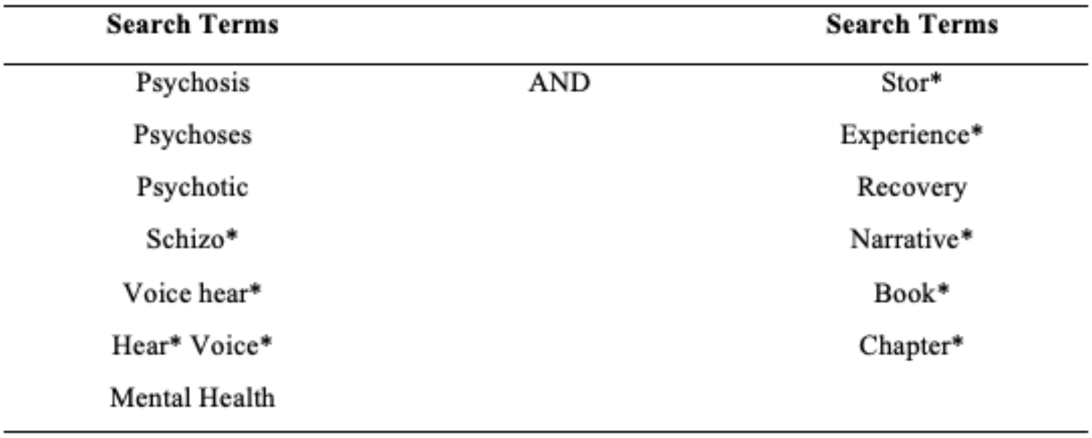
Due to recruitment challenges, the interview data was complemented using MH journey or recovery stories published in books. Books were identified by conducting a search on Google, Google Scholar, Amazon, and PsycInfo using the search terms illustrated in Table

2. The books were screened by the author to identify ones containing stories from ethnic minority voice-hearers.

Only stories told from a first-person perspective were selected as language is an important aspect of qualitative analysis (Braun & Clarke, 2022), and it was important to consider the language used by the individuals describing their experiences. Journal articles were not considered as they rarely meet the first-person account criteria. The search identified eight stories which related to the research questions (seven book chapters and one autobiographical book), all varying in length and depth. Table 3 lists these stories, and Table 4 illustrates the identities of the storytellers.

Table 2.

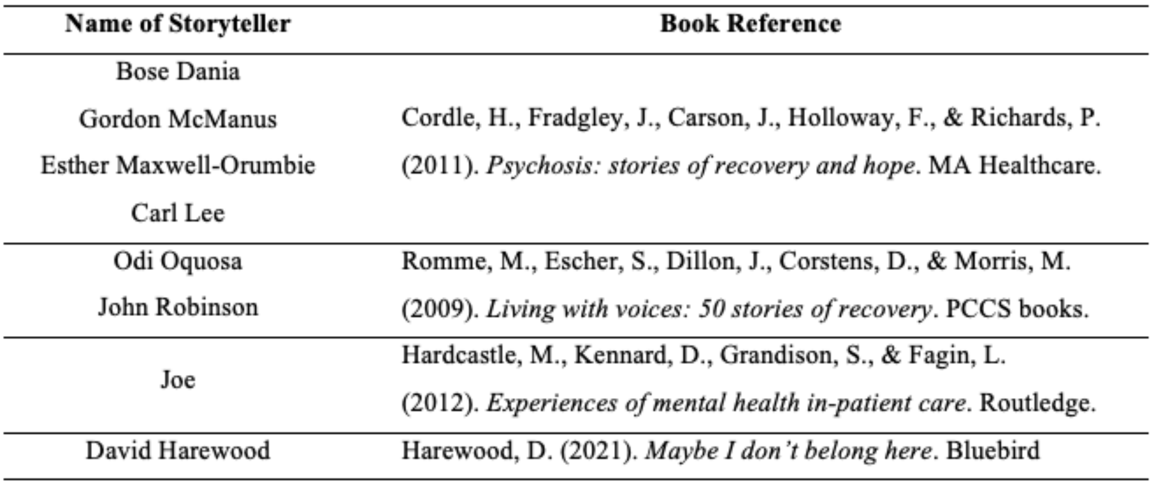
List of search terms used.



Search Terms		Search Terms
Psychosis	AND	Stor*
Psychoses		Experience*
Psychotic		Recovery
Schizo*		Narrative*
Voice hear*		Book*
Hear* Voice*		Chapter*
Mental Health		

Table 3.

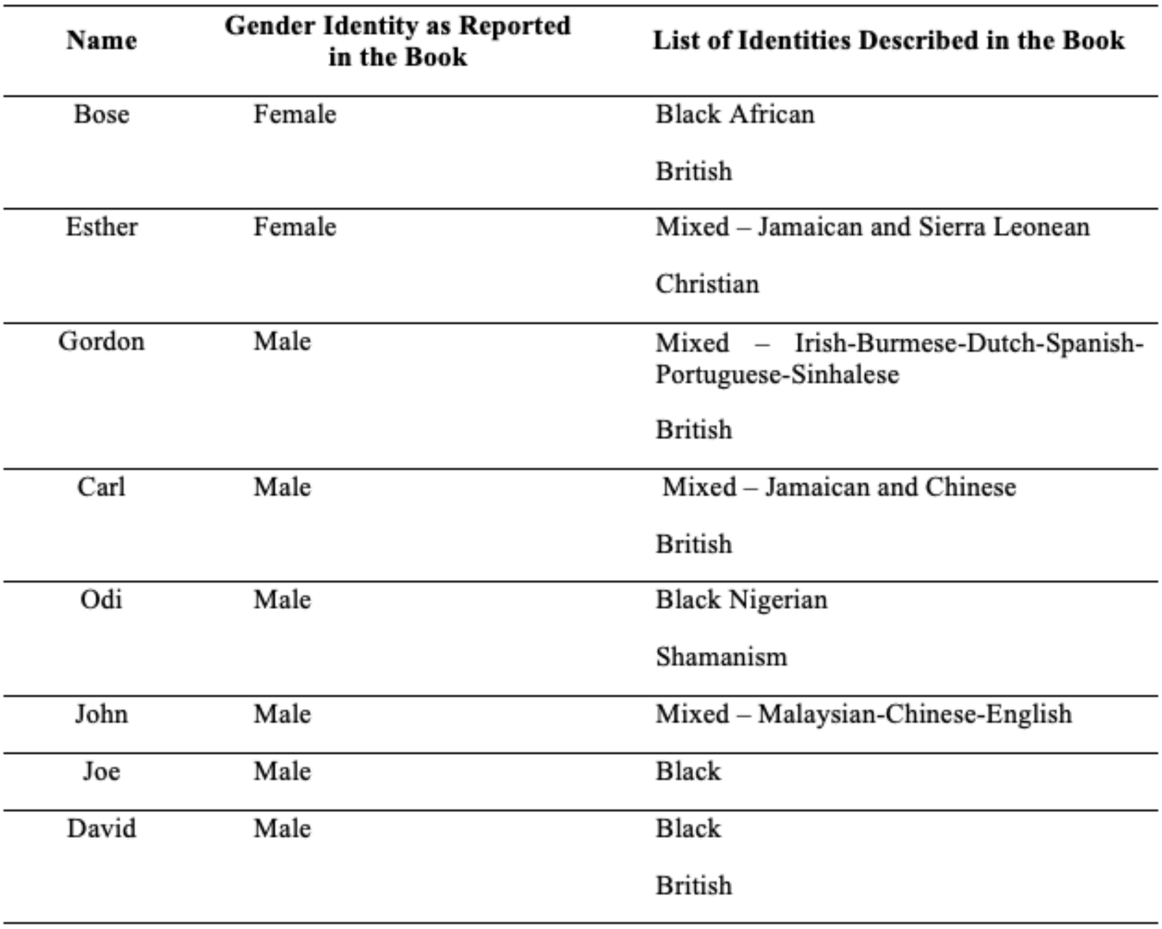
List of stories identified and their corresponding books



Name of Storyteller	Book Reference
Bose Dania Gordon McManus Esther Maxwell-Orumbie Carl Lee	Cordle, H., Fradgley, J., Carson, J., Holloway, F., & Richards, P. (2011). *Psychosis: stories of recovery and hope*. MA Healthcare.
Odi Oquosa John Robinson	Romme, M., Escher, S., Dillon, J., Corstens, D., & Morris, M. (2009). *Living with voices: 50 stories of recovery*. PCCS books.
Joe	Hardcastle, M., Kennard, D., Grandison, S., & Fagin, L. (2012). *Experiences of mental health in-patient care*. Routledge.
David Harewood	Harewood, D. (2021). *Maybe I don't belong here*. Bluebird

Table 4.

The storyteller's description of their identities



Name	Gender Identity as Reported in the Book	List of Identities Described in the Book
Bose	Female	Black African British
Esther	Female	Mixed – Jamaican and Sierra Leonean Christian
Gordon	Male	Mixed – Irish-Burmese-Dutch-Spanish-Portuguese-Sinhalese British
Carl	Male	Mixed – Jamaican and Chinese British
Odi	Male	Black Nigerian Shamanism
John	Male	Mixed – Malaysian-Chinese-English
Joe	Male	Black
David	Male	Black British

Materials

Materials used in this study included the research advertisement poster (Appendix D), the participant information sheet (Appendix E), consent form (Appendix F), debrief sheet (Appendix G), and interview schedule (Appendix H).

The interview schedule comprised of open-ended questions about participants' experiences and perceptions, and was used only as a flexible guide to ensure the interview was not constrained by the questions (Kallio et al., 2016). The first few questions explored participants' experiences of their cultural identities and of being an ethnic minority in the UK. This was followed by questions exploring participants' experiences of HV. Participants were then asked about their experiences of navigating different explanations and their relationship with their voices over time. The last question focused on exploring what participants found helpful to highlight their strengths and current support networks. Two members of the Salomons Advisory Group of Experts by Experience were consulted in the development of the interview schedule.

Interview Procedure

Individuals who showed interest were emailed the information sheet and a brief telephone call with the author was arranged. During the call, potential participants could ask questions about the research, and they were asked about support systems they had available to them and information about someone they would be happy for the author to contact in the unlikely event they became distressed during the interview. A date for the interview was then arranged and the consent form was emailed to the participant for completion.

The interview was conducted via Zoom and recorded using a dictaphone. Participants were given the information sheet again, and the consent form was revisited. The interview was conducted by the author and lasted approximately 90 minutes (Range: 86 minutes – 97 minutes). After the interview, participants were given the debrief sheet and the author asked about their wellbeing. All participants opted-in to receive a summary of this study, which has been emailed to them (Appendix I).

Ethical Consideration

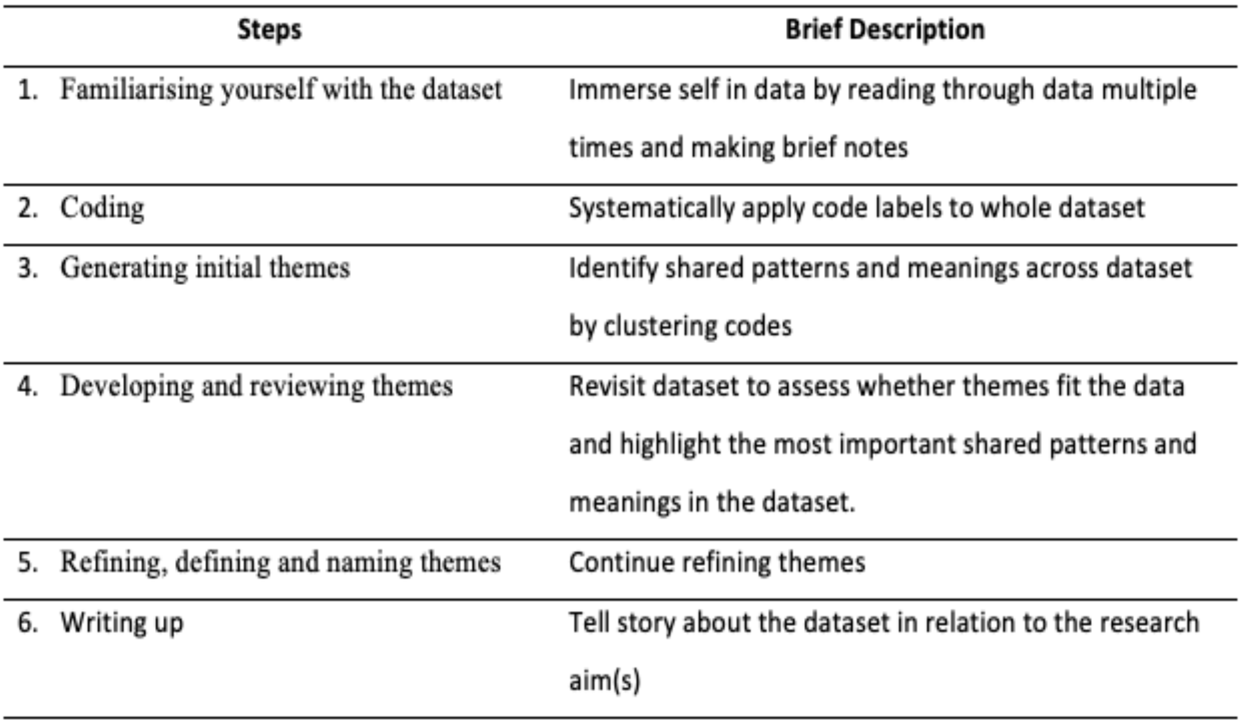
This study received ethical approval from Salomons Institute for Applied Psychology Ethics Panel (ETH1920-0338; Appendix J). In relation to data protection, only the author had access to participant identifying information. Recordings were immediately transferred to an encrypted memory stick after the interviews, transcribed as soon as possible, and then immediately deleted. All interviews were transcribed verbatim by the author, with identifying information removed to maintain confidentiality.

Data Analysis

Both interviewees and storytellers will be referred to as “participants” henceforth. To aid readers in distinguishing interview data and story data in the results sections, interviewed participants will be referred to as ‘Interviewee1/2/3/4’, and storytellers by their first name. The reflexive thematic analysis was carried out following the steps outlined by Braun and Clarke (2022, p.35-36) as summarised in Table 5 and illustrated in Appendices K-M.

Table 5.

Reflexive thematic analysis steps.



Steps	Brief Description
1. Familiarising yourself with the dataset	Immerse self in data by reading through data multiple times and making brief notes
2. Coding	Systematically apply code labels to whole dataset
3. Generating initial themes	Identify shared patterns and meanings across dataset by clustering codes
4. Developing and reviewing themes	Revisit dataset to assess whether themes fit the data and highlight the most important shared patterns and meanings in the dataset.
5. Refining, defining and naming themes	Continue refining themes
6. Writing up	Tell story about the dataset in relation to the research aim(s)

Reflexivity and Quality

“Reflexivity is an integral part of ensuring the transparency and quality of qualitative research” (Korstjens & Moser, 2018, p.120). Reflexivity considers the researcher’s role, perceptions, expectations, and assumptions, and the impact of these throughout the research process (Braun & Clarke, 2022).

The author of this research identifies as a female, Southeast Asian, Muslim, non-British, trainee clinical psychologist. These identities likely influenced data collection and development of themes. For example, as the author identifies as an ethnic minority, she had preconceived assumptions and experiences of systemic racism, which influenced the exploration of the research topic and development of the research question.

In relation to data collection, interview participants often alluded to the shared experience of discrimination between themselves and the author when speaking about racism. Although this may have helped build rapport and help participants feel comfortable in sharing their experiences, they may have had their own assumptions about what the author was looking for and tailored their answers accordingly. Although the author tried to mitigate this by asking open-ended neutral questions, it is impossible to completely remove bias and the researcher's influence in qualitative research since the researcher is a part of the study (Braun & Clarke, 2022; Roulston, 2013).

The author utilised several strategies to aid reflexivity. Firstly, a bracketing interview was conducted with another trainee clinical psychologist, helping the author identify some of her preconceived assumptions, expectations and hopes in relation to the research (Roulston, 2013). The author also kept a reflexive journal, documenting her thoughts and reflections, and how these may have transformed as the research progressed (Braun & Clarke, 2022). Appendix N presents a copy of the abridged reflexive journal which includes the author's reflections from the bracketing interview.

Additionally, the author worked closely with an experienced supervisor, having regular reviews to explore her reflections and the interpretations and decisions made (Braun & Clarke, 2022). Finally, the author aimed to gain interview participants' feedback regarding the themes developed to ensure the themes represented their experiences. However, due to time constraints, feedback from participants is still awaited.

Results

The life stories of the four interview participants are summarised in Table 6. This was done to help connect their life stories to the stories published in the books, and to provide context for the themes derived. Following analysis, six themes were derived from the data (Figure 2).

Table 6.

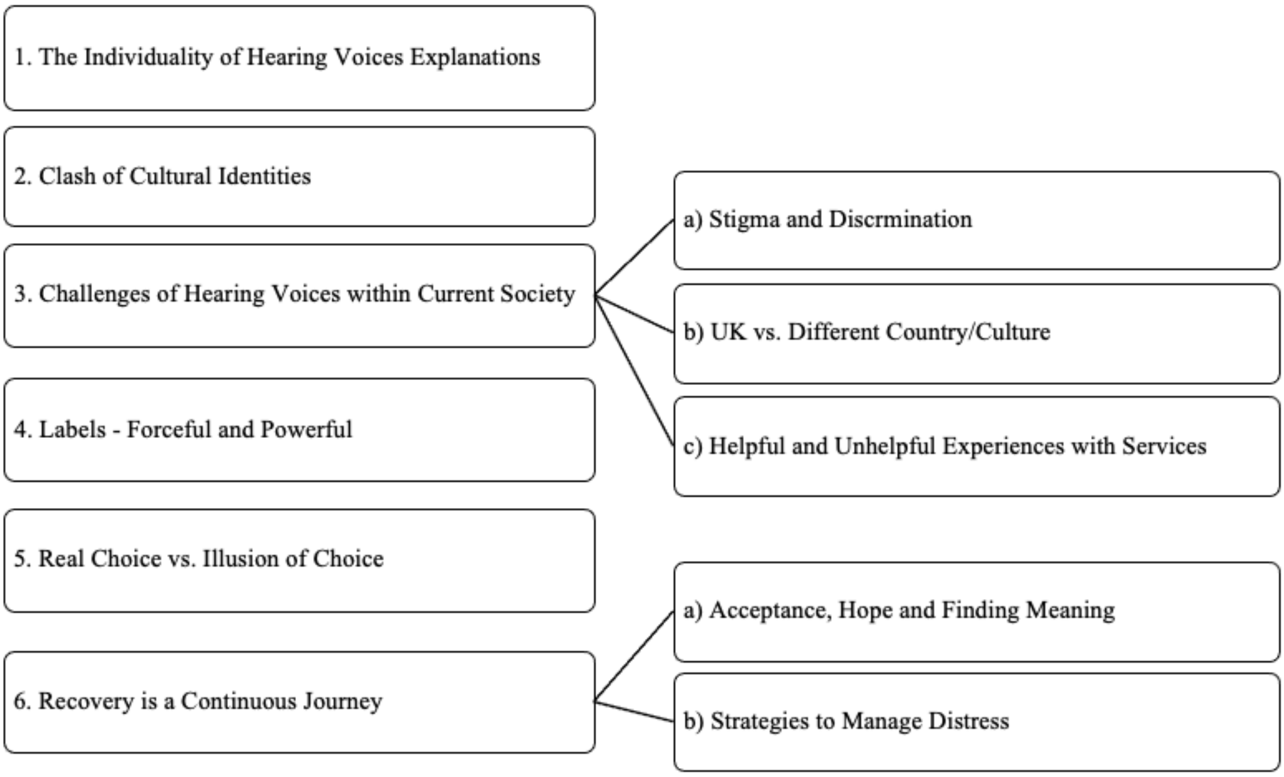
Summary of interview participants' life stories

Participant	Summary of Story
Interviewee1	Interviewee1 explained that he was born in a different country and moved to the UK with his siblings when he was a young child, and stayed with relatives. He provided accounts of needing to adapt and be someone who "makes the best out of everything". He also spoke about experiences of discrimination and not belonging within school, due to aspects of his identities. Although he explained that he felt connected to all aspects of his identities and was able to adapt, he also explained feeling connected to "none" at the same time. In relation to hearing voices, he explained that he had always heard voices, however, it became distressing whilst he was at university. He also added that he experienced multiple life stressors, such as a bereavement, during this time. Interviewee1 described first going to see his GP when he felt that his "perceptions" were "not right". He described having some religious-based explanations of hearing voices, such as the voices was the voices of Shaytan (devil) or was trying to get him away from God. After seeing his GP, he expressed feeling as if his GP was trying to "push" the diagnosis of schizophrenia on him, and thus he chose to leave and see a different GP. From here, he described multiple accounts where he felt as if others were trying to push the diagnosis of Schizophrenia or medication on him, against his will. Interviewee1 described these experiences as stressful, exhausting, and one which made him feel powerless. He also added that it made him feel not "normal" and felt as if he did not belong. He also added that he understood the diagnosis "schizophrenia" as meaning that he was "crazy". He described similarities between his experiences of hearing voices and experiences of being an ethnic minority in relation to discrimination and not belonging – e,g, not being British enough, or nor being normal enough. He also spoke about the possible benefits of hearing voices in other countries, where he felt individuals with MH diagnoses may have more freedoms and treated more equally as others. He also explained that his religion and faith has been most helpful in his recovery journey.
Interviewee2	Interviewee2's parents immigrated to the UK and she was born and raised in the UK. Interviewee2 explained that she was raised "British" and her parents emphasised that she had to speak like British individuals and that the British culture was more important than the West Indian culture. Interviewee2 expressed that this made it "tricky" growing up, and also described accounts of experiencing discrimination and racism since a young age. In relation to hearing voices, Interviewee2 explained that her whole family heard voices and saw "ghosts", and that it was something normalised within her family and culture. According to her culture, hearing voices was considered a gift. Interviewee2 also described a bad experience telling a teacher about hearing voices, and subsequently decided that she would never again speak to a British person about voices. Interviewee2 spoke about how hearing voices within the British culture is associated with a lot of stigma, is considered "insanity", and the pressure to conform with society and act "normal". She compared this to hearing voices within the West Indian culture where people are treated with "respect" and as "individuals". Interviewee2 also explained that her culture and family helped her normalise her experiences, and as a result she was not scared of the voices whilst growing up. Interviewee2 also described not trusting mental health services within the UK. Interviewee2 explained that she avoided mental health services for herself as a result of mistrust, however she accessed mental health services for her son who also heard voices. She described negative experiences with mental health services and feeling misunderstood. However, she described valuing the hearing voices group where people openly talked about their experiences, and stated that the UK needed more groups like this.

Interviewee3	Interviewee3 described growing up in the UK and living in various cities. As a result, he described having to adapt his behaviour according to his environment – e.g. whether his surrounding was more British or more Asian. He also reported multiple experiences of discrimination and racism throughout his life. Interviewee3 reported believing that the clash in his cultural identities and not knowing where he "fit in" were the reasons he started hearing voices. Interviewee3 explained that there is stigma around mental health and hearing voices within all cultures. As a result, he reported that he did not initially speak to others about his hearing voices experiences, which he felt made his experiences and distress worse. Interviewee3 explained that he eventually spoke to his GP, and added that he would only speak to professionals about his experiences due to stigma and discrimination. Interviewee3 emphasised that it was important to work alongside professionals and reach compromises as not doing so could lead to being hospitalised against one's will, and described a situation where a professional explicitly said this to him. He described having a positive experiences with mental health services and attributed this to his willingness to work with the professionals and compromise. He also described the fear of being hospitalised a s a motivator in his recovery. Interviewee3 reported that what has helped him the most in his recovery journey was his faith, keeping busy and building his support network. He also added that part of his journey to recovery has included the exploration of his various identities and trying to find his own identity.
Interviewee4	Interviewee4 explained that her parents immigrated to the UK when she was very young and she grew up in the UK. She explained that she lived a "western lifestyle" growing up. She reported that she started connecting to her Asian culture and practice her religion when she was older. Interviewee4 reported that she started hearing voices during this "transition". She also explained that the majority of the voices she heard were Asians, and added that she was bullied by Asians when she was a child. Interviewee described experiencing difficulties in navigating her different identities (e.g. Asian, Muslim, Western) throughout her childhood and adulthood. In relation to hearing voices, Interviewee4 explained that she used to believe what the voices said to her, and believed that the voices were demons. She explained that her family took her to see a faith healer, where she had an incredibly painful and negative experience. Interviewee4 described having both positive and negative experiences with mental health professionals. She described experiences where she was not believed or listened to, but also described experiences where she was able to negotiate her care. However, Interviewee4 later added that she felt as if her wants were considered and listened to only after she started conforming to the professionals' views of hearing voices. She also explained that based on her experiences thus far, she would not share her culture-based explanations with professionals as she believes "they would then think I was having another episode" and fears being sectioned. Interviewee4 explained that trying to explain hearing voices is stressful, and as a result has stopped trying to make sense of it and accepts that everything is from God. She explained that this belief has helped her in her recovery, alongside keeping busy.

Figure 2.

Themes and Subthemes



1. The Individuality of HV Explanations

Almost all participants highlighted holding multiple explanations regarding HV, including religion or spirituality-based explanations (Interviewee1, Interviewee2, Interviewee3, Interviewee4, Carl, Bose; Esther, John; Odi), being persecuted (Bose, Gordon), biological explanations (Interviewee3, Interviewee4; Esther), and stress (Interviewee1, Interviewee3, Interviewee4, Esther, Carl, Gordon, David). Many participants attributed the start of their HV to an increase in stress, as described by Esther and Carl:

> "At first I didn't know why I had become ill, but later on thought that it may have been triggered by the stress of my BEd degree studies" (Esther, p.167)

> "Then something stressful would happen in my life so I would get the symptoms again, but more intense and traumatic" (Carl, p.148)

Participants highlighted different views around navigating multiple HV explanations. Some, such as Interviewee1, highlighted that by having multiple explanations you “get the benefits of both” and have “more options” to “improve things”. However, others, describe the process as “confusing” (Interviewee4) and a “struggle” (Interviewee3). This confusion and lack of understanding of their experiences was the reason some participants, such as Bose, sought help at a later stage of their distress:

> “There was a sense that something was wrong, but I didn’t know what it was. I just thought I could fight it if I kept on working” (Bose, p.97).

Fundamentally, the experience of navigating explanations was unique to each participant, and each found differing explanations helpful. Some participants, such as Interviewee4, reflected on the benefits of a medical-based explanation:

> “It’s like a logical explanation to explain away what I'm experiencing, even though it's it feels real […] the explanation is there to let me know that, no, you're not having a divine intervention as such, it is just a chemical imbalance in the brain”

Other participants, however, described feeling upset with the idea something was innately wrong with them, as illustrated by Esther: “I just didn’t like it and found it difficult to accept the implication that I had a malfunction in my brain” (p.167).

Similarly, some participants, such as Esther, found having a culture-based understanding difficult: “I had delusions about my son being the Devil which was very difficult because I love him very much” (p.169). While others, such as Carl, found culture-based explanations helpful in making sense of their experiences and mitigating fear:

> “I didn’t fear these things, because I was so sure that the voice I’d heard was God and He assured me I would be protected. If I didn’t have the reassurance, I would have been very scared” (p.146)

Some participants described making sense of multiple explanations by accepting that ultimately the explanation itself did not matter as all experiences are from God, as explained by Interviewee4:

> “Whether it's an illness, whether it's demons, whether it’s God himself, it's all coming from God, and God wants me to go through this experience […] And that's how I kind of justify or rationalise in my mind”

However, not all explanations were equally accepted within MH services. For example, Esther recalled how cultural-based explanations could be dismissed by professionals:

> “Lots of mental health professionals don’t believe in God, but they also think that you shouldn’t believe in God either. They think it sets you back and makes you worse which I think is very wrong […] I’m not just a lump of flesh, I am a spirit inside a body and my spiritual dimension must be recognised” (p. 170)

Conversely, Odi who believed his voices were premonitions given by his ancestors, highlighted an experience where his beliefs were eventually considered, resulting in professionals seeing him as a “person”:

> “They [doctors] saw me as a mad person, who was delusional, as I was still talking with my voices. […] They asked to meet with some of my family and friends, so they came down and they said, ‘Yes, this is our culture’, so they stopped pestering me to take medication. They began to understand me by reading my poems and looking at my sculptures. They began to see that I wasn’t mad – I was a person” (p.252)

2. Clash of Cultural Identities

All participants held multiple cultural identities, and navigating these identities was often described as stressful, illustrating the impact of participants' context. Interviewee2, for example, highlighted the pressure to conform to the British identity:

> "My father insisted […] in order for you to survive in this culture, in this land, you have to speak the way they do […] learn the way they do. And so my father reinforced that in us, that Jamaican culture was not important. It was the British culture that was far more important"

Interviewee2 highlighted how this then impacted their ability to interact with their Black peers:

> "They [peers] look at me and say […] why are you speaking like that? Why are you behaving like that? That's not how we behave. That's not part of our culture. What you doing? And so, uhm, it was a bit tricky"

This ultimately created a sense of not belonging, and the feeling of identifying with "a lot of different backgrounds, but umm, like none really" (Interviewee1). As a result of this sense of not belonging, participants felt pressured to regularly adapt to their environment. The word "adapt" was used by all four interview participants.

Navigating different identities and the sense of not belonging ultimately created confusion and stress, with Interviewee3 and David specifically linking this to the start of their HV experience:

> "So at the time I wasn't sure where I fit in. I wasn't sure about who I was […] me being South Asian, me being British, me being Muslim. So I was having a bit of identity crisis […] and that resulted in me having a psychotic episode" (Interviewee3)

> “I see the roots of it [psychotic episode involving voice-hearing] as being a gradual build-up of stress and questions of identity around my race” (David, p.107)

3. Challenges of Hearing Voices within Current Society

a) Stigma and Discrimination

Participants referred to the different forms of stigma and discrimination they experienced. Firstly, it was stressed that individuals who hear voices are viewed as “the most insane people according to society here” (Interviewee2). Consequently, many participants recalled their apprehension in sharing their experiences with others, as illustrated by Carl: “there is a stigma about it and you don’t want to share it with friends or other people” (p.149)”. Moreover, Interviewee2 described stigmatising remarks after telling a teacher:

> “I remember being at school and telling my teacher. And them looking at me and saying, ‘here we go, we got a nutter here’, […] never speaking about it again. And I knew what the reception would be if I ever spoke about it to anybody. So I kept it to myself”

As a result, Interviewee2 highlighted they would “never ever speak to a white person, a British white person, about a ghost”. Therefore, to avoid judgment and dismissal, it is understandable why voice-hearers may choose to hide their experiences. However, this could consequently mean voice-hearers may not seek support until their distress is severe, as highlighted by Interviewee3:

> “When I was growing up I didn't talk about mental health and that's how I think some of the problems started. If at an early stage I I talked to someone […] they might have still helped me uh, understand it better”

However, Interviewee3 also highlighted that even if they were to tell others about their experiences, they may not be believed, thus invalidating their experience:

> "I think there's a general consensus. So if I if I go up to someone and say I hear voices. They, they'll be uhm, reluctant to believe me or they might not believe me, or they might say you're not telling the truth"

> Bose views this disbelief as a denial of distress, commenting that this may be because HV is an invisible experience: "no one understood I was ill and my family said there was nothing wrong with me. When the illness is in your head, people expect you to act normally" (p.102).

Joe also stated "there is a stereotype that seems to go with people like me, a person of colour who has a mental health label", emphasising there may be added stigma and discrimination for ethnic minority voice-hearers. Moreover, many participants reported experiences of stigma and discrimination associated with their ethnicity dating back to childhood. For example:

> "if you couldn't speak English at school you were sent into the educationally subnormal class. This injustice disturbed me and I wanted to get rid of it by fighting for the Black students' right: (Gordon, p.125)

> "When I was seven years old […] It was an incident I'll never forget for it created a rupture that lasts until this very day […] his face a picture of hatred and anger, he leaned in towards me and said, 'get the fuck out of my country, you little Black bastard!' […] I was shocked and rooted to the spot" (David, p.10)

b) UK vs. Different Country/Culture

Participants highlighted the differences in how MH, HV, and diagnostic labels are perceived within various cultures. Some participants reported the British culture to be "understanding" and "open" (Interviewee3) whilst others reported it to be filled with "stigma" and voice-hearers will be "ostracised" (Interviewee2). Similarly, many participants highlighted how HV in their non-British cultures is normalised as "people would just treat me like a, like a, like the same as everyone else" (Interviewee1) and they could have a "normal life" (Interviewee2). However, others highlighted the immense stigma present within their respective cultures, with Interviewee4 highlighting "I think I'd probably be dead if I were in Pakistan. I think they would have beaten the beast, the Devil out of me". Ultimately, as highlighted by Interviewee3, "in every culture there's discrimination in terms of mental health".

Participants also highlighted both the advantages and disadvantages of HV in the UK, especially in relation to their daily life. For example, Interviewee1 highlighted the "safety net" and "protection from the government". However, Interviewee1 also reflected on the downside of this "protection", especially when combined with stigma:

> "If you wanna work and you have mental health, there's a, there's literally like no chance. […] if you want a relationship in the in the UK, uhm there's like the stigmas associated to mental health. […] I understand they try to protect you, but at the same time, like I don't know like it seems like it's a struggle between oppression and uh protection"

c) Helpful and Unhelpful Experiences with Services

All participants (except John) had experiences with MH services in the UK. There were mixed views around the helpfulness of MH services, with many reporting both positive and negative experiences.

Positive experiences were reported by those who felt they were being listened to and understood, as reported by Carl:

> "The most help I've had is when I've been able to talk about what I've been going through, they listen and say they understand, not that I'm mad" (p.148)"

Conversely, negative experiences centred around feeling unsupported, uncared for, and a “lack of compassion” (Interviewee 1), as highlighted by Bose:

> “People with mental illness want to rebuild their lives but don’t know how. All they need is a little support and guidance. But you don’t get that in hospital, they just leave you there on medication” (Bose, p.99)

Ultimately, Interviewee1 highlighted that one’s experience with MH services may be dependent on luck: “it's like a postcode lottery. Like you know, like depending on where you live in that kind of, that's the kind of care you would get, you know”.

4. Labels - Forceful and Powerful

Throughout their journey with MH services, participants highlighted their experiences in receiving a schizophrenia or psychosis diagnosis, with many participants describing the lack of choice in this matter, highlighting that MH professionals “diagnosed me with schizophrenia” (Odi, p.252) and “they’re trying to say I’m mad” (Bose, p.99). Some participants commented that a MH professional’s “job is to diagnose” (Interviewee4) and many participants believed these diagnoses meant they were “insane” (Interviewee2) or “crazy” (Interviewee1), illustrating the power labels can carry.

A common narrative amongst participants was that they themselves did not think they deserved the label, especially at the beginning of their experiences. For example, Interviewee2 highlighted “I don't want to be given that label because I'm not insane”. Interviewee1 also highlighted how being labelled may have challenged his identity of being “normal”: “I grew up feeling normal and thinking normally with normal perceptions […] all of a sudden, all of a society trying to tell me I'm a crazy person”. Similarly, Carl highlighted the difficulty in trying to accept a label, and the loss of self and stigma that may come with it:

> “The biggest word is ‘disability’ – you have to accept that you are a disabled person, like you have had your legs chopped off. Before you were a man of the world and could take on anything but all of a sudden you have got this stigma that you are disabled” (p. 149-150)

When asked if he had a say in being diagnosed, Interviewee1 explained: “No […] I wasn't given like uh, […] like a proper self-defence of being defined as a kind of a crazy person or Schizophrenic”. This powerlessness then contributed to added distress, as further highlighted by Interviewee1:

> “I just needed a break I, I didn't wanna be schizophrenic, I didn’t wanna be defined as schizophrenic. […] all these people trying to define me and make me do something against my will and push me aside”

Additionally, the fear of being labelled may have also acted as a barrier to seeking help, as illustrated by Interviewee3 and Interviewee1:

> “I had my own preconceptions and I didn't want to be labelled as the service user of mental health, because it stops you from doing things” (Interviewee3)
>
> “So a part of me wanted to like, uh, seek help because I needed not to be a danger. But at the same time, I didn't want the definition of schizophrenia” (Interviewee1)

5. Real Choice vs. Illusion of Choice

Choice was a consistent theme across all the interview data and stories. Some participants recalled experiences where they were given a choice in relation to their care. Interviewee3, for example, explains the choices he had in relation to choosing which group activities he participated in: “they had a walking group, they had a cooking group, they had a pool group, they had a gym group. So you get to participate and you get to make choices”.

However, some participants, such as Carl, also recalled experiences of not having a choice: “After the first experience with the tablets, I said I wasn’t going to take them anymore. This young doctor said that if I didn’t, they had a right to hold me down and inject me” (p.147)

The concept of choice was not clear cut and became more complicated as some participants also gave examples of what seemed to be the illusion of choice, instead of real choice. For example, Interviewee4 reflected that the doctors were open to negotiating her medication only after she conformed to their understanding of HV:

> “Ever since I've started to tell the psychiatrist that I don't know what it [voices] is, because I used to think that it was the God or the demons or angels and whatever […] I've noticed that they seem to hear me more. And they kind of accept what I'm saying a bit better […] because I'm rational, I'm able to function well, and I'm seeing it as a understanding in a way that they see their understanding, they are more open to me having suggestions like not increasing medication”

This illustrates that voice-hearers may feel pressured to conform to the explanations laid out by MH professionals to be perceived as “rational” and have a choice about their care. Similarly, some participants highlighted the pressure to conform to avoid hospitalisation, as illustrated by Interviewee3:

> “They [MH professionals] said to me, ‘look if you don't work with us, you're going to go to hospital’ […] so I was a bit scared, and I was nervous, and I was confused […] they want to talk to you, they ask you to come to appointments. And if you don't, if you're not well, then they can put you in hospital”

This questions the idea of choice, as although working collaboratively with professionals may imply the presence of choice, the threat of being hospitalised suggests it may not be a real choice. Additionally, the lack of information provided was also highlighted which further suggests the absence of real choice, as illustrated by Interviewee1: “they don't really explain to you why they prescribe you that […] and the benefit, and how it will work”.

As a result of this, Carl and Bose highlight the importance of knowing one’s right to be able to fight for real choice:

> “Eventually my mental health solicitor got a court order for me to be released. My solicitor became like my protector – I would call her whenever they wanted me to go back into hospital and she would offer me her service” (Carl, p.147)

> “[I] got more information on mental health, finding out that I had rights and didn’t have to take the medication I was given” (Bose, p.99)

6. Recovery is a Continuous Journey

a) Acceptance, Hope and Finding Meaning

Participants reflected both that “mental illness is for life” (Bose, p.102), and that “recovery is possible” (Esther, p.170). Many participants reported still hearing voices but no longer experiencing the same level of distress, illustrating that recovery was not always synonymous with eliminating voices. Participants highlighted the importance of accepting the voices and their experiences in order to start their journey to recovery, as illustrated by Gordon: “recovery becomes easier once you confront the illness” (p.129). Additionally, participants highlighted the importance of having hope and sense of purpose in recovery:

> “Hope is fantastic in helping with recovery […] I always knew that however long the road was, there would always be something good further along. This positive outlook has helped me with my recovery” (Esther, p.171)

> "People like to feel purposeful and because you're suffering from a condition it doesn't mean you become obsolete […] they need to balance the patient's therapy with whatever their dream or purpose is" (Carl, p.149)

Each participant found their own unique ways of defining recovery and the steps to towards it. Gordon, for example, developed his own model of recovery focused on rebuilding himself**:**

> "I developed a model of my own recovery […] The model shows a journey from normality, through hospital breakdown and schizophrenia, into a stage of recovery which hopefully leads back to a period of normal life" (p.128-129)

Others, such as Esther, defined recovery as having the knowledge to recognise and manage their symptoms of distress: "I know I am on the road to recovery because my insight is still intact. If I begin to get some symptoms I know what I should be doing" (p.170)

Ultimately, most participants described recovery as a continuous lifelong process, and credited their own personal strength and resilience in starting this journey: "And when things got tough […] I relied on the resilience and strength I cultivated whilst ill to get me through" (David, p.181)

b) Strategies to Manage Distress

Participants recalled various strategies they found helpful throughout their HV journey. Firstly, medication was reported to be both helpful and unhelpful. Participants reported some medication enabled them to think "rationally" (Interviewee4), and feel "calmer" (Gordon, p.128), whilst others brought upon "side effects and stuff" (Interviewee1) and made them feel like a "zombie" (Carl, p,147). This illustrates how medication impacts individuals differently.

Secondly, talking, both to professionals and other people, was described as beneficial in reducing stress and helping participants make sense of their experiences and identities, as illustrated by Gordon: “this [therapy] was very helpful in enabling me to talk about my condition instead of keeping it in my head. It removed a lot of stress and helped me begin to recover” (p.128), and Interviewee3: “when you talk to someone else about it and explain it to them and then they tell you or you try to understand it, then that helps you with your identity”.

Furthermore, many participants emphasised the role of spirituality in managing distress and voices, such as Esther: “My belief in God has helped me a great deal in my recovery journey […] I am now more focused in my Christian life and don’t compromise anymore” (p.171). Hence, the importance of professionals understanding the role of spirituality was emphasised, as illustrated by Carl:

> “The main problem a lot of doctors have is that they have very little idea of the spiritual beliefs of their patients. They view your illness on a medical pathway […] If you are dealing with people who are going through what they deem as a spiritual experience, you should have some basic idea what they are talking about” (p.149)

Lastly, keeping busy and engaging in activities was highlighted as an important strategy, as highlighted by Interviewee3:

> “I tried to put support mechanisms in place and using the app [Brain in Hand] is one of them. Keeping a sports diary is another one. Talking to someone like yourself is another one. Going for a walk is another one. Going to the gym is another one. So all those small things have played a, played a role in helping me get better”

Discussion

This study aimed to explore ethnic minority voice-hearers' experiences and perceived impact of being immersed within and navigating UK western society and explanations of HV.

The findings highlight the various HV explanations held by participants and demonstrate the complexities and confusion associated with navigating these explanations. The findings suggest there is no one right explanation for voice-hearers, with many reporting differing explanations as helpful. Romme and Escher (1989) suggest that attributing meanings to one's voices, which they termed as having a "frame of reference" (p.213), is an important step to building a positive relationship with voices, which subsequently can help reduce distress. For example, a qualitative study by Taylor and Murray (2012) found that participants' spiritual explanations for their HV experiences were associated with a perceived reduction in distress, provided a sense of control over their experiences, and increased a sense of purpose in their lives. Therefore, it is important for professionals to support voice-hearers in making sense of their voices in a way that makes sense to them, and not just one that fits with specific diagnostic criteria.

The findings also illustrate that many participants attributed the start of their voices to an increase in stress, in line with previous literature (e.g. Ally & Brennan, 2015; Schofield et al., 2019; Weich et al., 2010). This supports the Traumagenic Developmental Model of Psychosis, which posits childhood adversities could increase one's vulnerabilities to 'psychosis' experiences such as HV (Read et al., 2001; Read et al., 2014). As individuals from ethnic minority groups may be faced with a greater number of inequalities across various domains (Byrne et al., 2020) and psychological trauma due to racism during childhood (Harewood, 2021), such experiences may be increasing ethnic minority individuals' risk of developing these vulnerabilities.

Moreover, supporting Bhugra’s (2004) idea of acculturation, participants highlighted the difficulties and increased stress in navigating multiple cultural identities, with some attributing the start of HV to this stress. Berry (2007) suggests that integration, as opposed to assimilation, is the process where an individual is able to combine both their culture of origin (e.g. Asian) and the dominant culture (e.g. British). According to Bhugra and colleagues (2010), “integration can only be chosen as an option by the minority group when the dominant society is open and inclusive towards cultural diversity” (p.542). The findings of this current study highlight possible difficulties in integrating, with many participants reported experiencing the process of marginalisation - where the individual feels as if they do not belong in either culture. According to Berry (2007), when an attempt at assimilating with the dominant culture is met with hostility from the dominant group, the marginalisation process is inevitable. It could also be argued that participants may have experienced difficulties integrating the voice-hearing aspect of their identity for these same reasons. Therefore, experiences of not belonging, stigma, and discrimination reported by participants (both in relation to their culture and HV) may have inhibited the process of integration, leaving participants feeling marginalised and distressed.

Goffman (1963) also suggests that social identity labels associated with undesirable attributes may lead to stigma, and subsequently taint one’s own sense of identity and decrease self-esteem. As highlighted in the findings, HV was often associated with the label “crazy” or “insane”, which may have challenged participants sense of being ‘normal’. Therefore, voice-hearers may have hidden their experiences from others as a way to protect themselves from these labels which could impact their own sense of identity. Additionally, Social Identity Theory posits that to continue to feel like one belongs within a group and be thought of positively, one may feel pressured to conform to the values, behaviour, beliefs and norms of the group (Tajfel & Turner, 1979). Hence, participants may have also hidden their HV experiences to conform to society and be part of the ‘norm’. Concerns about HV stigma acting as a barrier to help-seeking and accessing support has also been highlighted in previous qualitative research (e.g. Rathod et al., 2010; Vyas et al., 2021; Wagstaff et al., 2018).

The findings also highlighted a connection between participants’ experiences of HV and their experiences as an ethnic minority. Participants’ experiences of being labelled, stigmatised and discriminated against in relation to HV may be retraumatising as it may trigger similar past negative experiences linked to their ethnicity. Grossman and colleagues (2021) highlight that retraumatisation within healthcare settings “is especially true in communities that have been hurt by histories of, as well as current medical institutional practices that propagate and maintain collective traumas” (p.1). Therefore, considering the experiences illustrated in this study and current literature highlighting institutional racism within MH settings (e.g. McKenzie & Bhui, 2007; Nazroo et al., 2020), it is possible that voice-hearers from ethnic minority groups may be experiencing a form of retraumatisation, further increasing the distress experienced.

Furthermore, the threat of being labelled, hospitalised, or prescribed medication against one’s will could be described as a form of coercive practice (O’Brien & Golding, 2003). These subsequently acted as a barrier to accessing support, as echoed in the literature (e.g. Islam et al., 2015; Keating & Robertson, 2004; Rathod et al., 2010). Another form of coercive practice is the lack of choice (O’Brien & Golding, 2003). The findings highlighted the lack of information provided to participants about their experiences, treatment options, medication, and their rights. This is also present within previous qualitative research exploring the experiences of ethnic minority individuals with a psychosis diagnosis (e.g. Lawrence et al., 2021a; Lawrence et al., 2021a; Penny et al., 2009; Weich et al., 2010). Without adequate information and knowledge about one’s options, it is impossible for a person to make an informed choice about their care as outlined by the Mental Capacity Act (2005), questioning the ethicality of services offered.

Despite the possible stressors and shortcomings of MH services, the findings also highlight participants' resilience and how participants navigated their journey to recovery, focusing on acceptance, hope, purpose, spirituality, and valued activities. The findings also highlight the importance of voice-hearers being treated as individuals and having individualised care. These are echoed by previous qualitive research exploring recovery with those diagnosed with psychosis (e.g. Pitt et al., 2018; Windell & Norman, 2012). The findings suggest that although many participants still reported hearing voices, a process of acceptance and learning to live with their voices was central in the process of recovery. This is supported by current research which suggests accepting voices and reacting to voices in non-resisting ways was associated with increased control over experiences and lower distress (Farhall & Gehrke, 1997; Vaughan & Fowler, 2004). It is thus important for these factors to be incorporated into the care offered to individuals who hear voices, and focus on improving voice-hearers relationship with their voices instead of attempting to eliminate voices.

Limitations

The findings from this study should be considered in the context of its limitations. Firstly, due to the recruitment difficulties encountered, the interview sample lacked in diversity and sample size. Although the stories from books broadened the demographics, the stories were not as detailed or focused as the interviews. Hence, future research would benefit from recruiting a larger sample of participants.

Additionally, although the reflexive thematic analysis process and quality measures have been outlined in detail, the analysis was conducted by only one researcher. Braun and Clark (2022) suggest having multiple coders is not essential, and that having a single coder is both "normal" and "good" practice within this approach (p.55). Nevertheless, having an additional coder or an independent auditor could reduce some researcher bias and increase the credibility of the process (Korstjens & Moser, 2018).

Moreover, the current study only explored social categories such as ethnicity, culture and religion. However, there are various other identities participants may identify with, including identities linked to sexuality, social class, and gender (Burnham, 2012). Therefore, future research should consider the concept of intersectionality, exploring how voice-hearers may navigate the different aspects of their interlaced identities, and the impact this may have on their HV experiences.

Clinical Implications

Participants highlighted a desire for MH professionals to consider their understanding and meanings of their experiences. Hence, professionals could be more flexible in their practice and meaningfully acknowledge and respond to individuals' beliefs about their HV experiences, and support voice-hearers to build a more positive relationship with their voices.

The benefits of considering voice-hearers' own cultural understanding has been demonstrated by research illustrating the increased efficacy of culturally adapted interventions for psychosis (e.g. Degnan et al., 2018; Rathod et al., 2013). Furthermore, Steel et al. (2020) found the "Makin Sense of Voices" (p.107) approach was rated positively overall by NHS patients within their sample. Moreover, Rousseau and colleagues (2005) found that acceptance and recognition of non-western beliefs and views aided in reducing power imbalances.

Furthermore, considering the additional stressors faced by individuals from ethnic minority groups, and the possibility of retraumatisation, it is important that MH professionals and services keep in mind and acknowledge the possible impact of racism (be it individual or institutional) on people's lives and experiences, and incorporate the principles of trauma informed care in their practices (e.g. Sweeney et al., 2016). The findings also highlight the importance of exploring individual's acculturation experiences and the impact this may be having.

It is important for MH professionals to ensure individuals are given adequate information and choice about what is happening, diagnosis, and their treatment options, to enable them to make informed decisions (DHSC, 2018; Mental Capacity Act, 2005). The findings highlight that accounts of positive experiences with MH services revolved around being listened to, highlighting the importance of listening to voice-hearers' needs and decisions.

Additionally, the findings highlighted there is no one specific treatment option or strategy that helped all the participants. For example, some participants found medication helpful whilst others found it unhelpful. Hence, the care and options offered to voice-hearers should be individualised and tailored to their needs, taking into account their wants, goals and hope for the future, and ultimately voice-hearers should be the one to make the decision about their care.

As highlighted above and in previous sections, existing research has illustrated the possible role of trauma, life stressors, and racism on experiences of hearing voices, and the possible benefits of considering cultural beliefs and practices within treatment and care. However, based on the findings of this study and previous qualitative studies highlighted in the introduction, these findings do not appear to have been incorporated into clinical practice. Boyle (2011) suggests that psychology is still a growing field, and may experience "extreme insecurity about its academic and social acceptance as a science" (p.37). As a result, psychologists may take a step back in multidisciplinary settings or may not feel able to challenge long-standing psychiatric practices or existing service norms based on the medical model. Therefore, to promote real change and improve the care offered to ethnic minority service users, clinical psychologists may need to take a more assertive position within teams and encourage services to incorporate the above findings and suggestions into formulations and clinical practice.

Conclusion

The current study explored ethnic minority voice-hearers' experiences and perceived impact of being immersed within and navigating UK western society and explanations of HV. The findings highlight the various HV explanations held by ethnic minority voice-hearers, with an emphasis on the role of stress. The findings suggest that one's identity as an ethnic minority may be associated with additional stressors in one's life, which may subsequently increase vulnerability to experiences such as HV. Moreover, the findings highlight the complexities of navigating various explanations and social identities (cultural identities and voice-hearer identity). However, elements such as hope, acceptance, and purpose are salient in individuals' journey to recovery. Despite the limitations of this study, possible ways of improving clinical practice for ethnic minority voice-hearers is explored, focusing on making sense of experiences, reducing distress and improving autonomy and choice.

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Section C: Appendices

Appendix A

Thematic Synthesis Process: Example Quotes, Codes and Themes

No.	Example Quotes	Codes	Descriptive Themes	Analytical Themes	Studies Theme is Present In
1	Mrs. Saeed: All the relatives and I know that it could be black magic, as it has been done to a lot of people. (Penny et al., 2009)	Religious/spiritual explanations of mental illness	Various explanations to understand distress and illness	Explanations of Psychosis that do not Conform to the Western Medical Model	Penny et al., 2009; Rathod et al., 2010; Weich et al., 2010; Ally & Brennan, 2015; Islam et al., 2015; Schofield et al., 2019; Lawrence et al., 2021a; Lawrence et al., 2021b; Vyas et al., 2021
	Ideas of sin, wrong doing and punishment were sometimes associated with a religious explanation of mental illness. (Rathod et al., 2010)	Religious/spiritual explanations of mental illness			
	Unique to many African Caribbean respondents (patients and lay participants) was the belief that mental illness could be caused by a series of events whose origins were misunderstandings with the police, which then resulted in an arrest. (Rathod et al., 2010)	Mental illness was a consequence of being misunderstood			
	Maria: life was too tough and he couldn't work as he had no permission, so he had no money for food […] he used to feel when he walked on the street, wanted to get hit by car or jump in front of the train (Ally & Brennan, 2015)	Difficulties is a result of life stressors			
	. . . as soon as we smoke weed or we have alcohol we're not pure, our bodies are not pure so we are prone to attack from evil forces" (SU20, British Pakistani, male) (Islam et al., 2015)	Religious/spiritual explanations of mental illness			
	The ethnic minority experience is not the same as the native experience. Maybe we've had more struggles in life, and especially inner city and stuff like that, and basically the struggles that we have in life could turn us in a different direction. (Focus Group 2) (Schofield et al., 2019)	Difficulties is a result of life stressors			
	Being British-Asian, I think that we switch through things in a way that other people don't and we do it very quickly without even realising it. You flip between both worlds and you do that so quickly in different situations and I don't even know how much. I feel like there's a point with adaptability where it gets stressful, really stressful. Especially if you're trying to adapt to different cultures and you're doing it so much on the fly that you start to question your own beliefs, is this my belief or is this someone else's belief that I'm taking in (Anwar) (Vyas et al., 2021)	Adapting to different cultures is stressful			
2	She too was unhappy with the typical medical formulation (Chakraborty et al., 2009)	Unhappy with the medical model	Refuting the label given or the medical explanation	The Rigidity of The Medical Model Used Within Mental Health Services	Chakraborty et al., 2009; Penny et al., 2009; Rathod et al., 2010; Weich et al., 2010; Ally & Brennan, 2015; Islam et al., 2015; Schofield et al., 2019; Lawrence et al., 2021a; Lawrence et al., 2021b;
	It was striking that none of the participants used the terms psychosis or schizophrenia at all in the interviews and very rarely described any of the more typical "positive" symptoms of psychosis (Penny et al., 2009)	Labels not used by participants			
	Several rejected the notion that they had had mental health problems ascribing their contact with services to the malicious intrusion of others or finding it a matter of puzzlement. (Weich et al., 2010)	Rejecting labels			
	A lot of us have been misdiagnosed because somebody thinks that if you're somebody from the Caribbean and you happen to mention something like, you had a vision: 'So you're seeing things then' (Focus group 1) (Schofield et al., 2019)	Misdiagnosis due to lack of cultural understanding			
	The narratives also revealed tension between accepting diagnoses and the need for treatment, and deeper beliefs that 'schizophrenia' and 'psychosis' signified madness (Lawrence et al., 2021b)	Tension in accepting the diagnosis as it signified madness			

	Contrary to this was the response from participants from BME communities that their background and models of illness were not understood (Rathod et al., 2010)	Participants own understanding of illness not considered	Psychiatry as being sterile, clinical, inflexible, and uncertain		
	Participants were perplexed and distressed by what they saw as the inflexibility of the medication-focused mental health services (Ally & Brennan, 2015)	Inflexibility of mental health services			
	they saw the unwillingness of the "system" to engage with community explanations and coping strategies as regards mental distress as a major barrier to healing. (Ally & Brennan, 2015)	Inflexibility of mental health services			
	First they said it was depression, and then bipolar, every time it is just getting worse […] It looks like they don't know what they are treating" (Ally & Brennan, 2015)	Trial and error nature of the medical approach			
	"Just that . . . we can't blame them because they're upbringing is like westernized, they can't understand if we talk about Jinns . . ." (SU20, British Pakistani, male). (Islam et al., 2015)	Professional's lack of understanding regarding cultural/spiritual perceptions of difficulties			
	My critique of psychiatry is like I said to you before if you don't believe in the spirit world then you, or even accept that it exists even if you don't believe in it, then you'll have a hard time coping with psychiatry especially in a multi-cultural way. I mean I don't know about English people, but especially with a multi-cultural approach, a realistic one, you'd have a very hard time, it's very sterile, a lot of it is very sterile and it is very clinical, and it's a narrow perspective of life. (Paula, BC) (Lawrence et al., 2021a)	Psychiatry is sterile, narrow and do not take a multi-cultural approach			
3	She has been admitted compulsorily in the past and received medication against her will. (Chakraborty et al., 2009)	Receiving medication against will	Medication and its side effects	Medication vs Psychological Therapy	Chakraborty et al., 2009; Penny et al., 2009, Rathod et al., 2010; Weich et al., 2010; Ally & Brennan, 2015; Islam et al., 2015; Wagstaff et al., 2018; Schofield et al., 2019; Lawrence et al., 2021a; Lawrence et al., 2021b; Vyas et al., 2021
	The majority of patient participants highlighted that although medication was helpful, it was probably being overused in BME patients (Rathod et al., 2010)	Medication overused amongst BAME patients			
	At best medication was cited as a necessary evil, at worst the cause of considerable additional problems (Weich et al., 2010)	Medication can be helpful and unhelpful at the same time			
	one service user expressed annoyance that staff would rush in and out with medication ''like a floating pharmacy'' (Weich et al., 2010)	Staff rush in and out with medication			
	When she started using the medication, I noticed her mouth was turning to the side; so she refused taking them […] so they took and admitted her to the hospital where she stayed for three months and they forced her into medication […] Her eyes went stiff and she could not blink […] They keep changing different medications […] but unfortunately the voices were still there", and she became physically ill as well (Ally & Brennan, 2015)	Side effects of medication			
	the medication is good and everything but it's not taking away the illness . . . I want the cure you know, we want the cure you know" (SU6, Black British African, male). (Islam et al., 2015)	Medication can be helpful and unhelpful at the same time			
	'Poison', 'allergic', 'mess up my head' are all expressions used to describe the experience of being on psychotropic medication (Wagstaff et al., 2018)	Side effects of medication			
	I don't think that's true (that people from minority groups receive poorer services). I don't think, because when it comes to receiving any treatments regardless I have never seen any situation: 'this is for Black people this is for white people'. The medication is all the same. (Focus Group 4) (Schofield et al., 2019)	Medication as treatment is the same for all ethnicities			

	Val (BC) expressly stated that she took this decision herself as she felt that her doctor would dismiss her concerns. Frequently, however, this led to a worsening of symptoms and repeat hospital admissions, thereby having the perverse effect of diminishing individuals' sense of agency. (Lawrence et al., 2021a)	Decision dismissed by doctors			
	Others described a commitment to taking medication that had been established after finding the optimal dosage in partnership with community mental health professionals who many discovered were often sympathetic to the negative effects of medication. They chose to tolerate any remaining side effects as they had come to understand that medication enabled them to live their lives as fully as possible (Lawrence et al., 2021a)	Medication tolerated when shown empathy/listened to			
	I didn't know what I was taking, they didn't explain to me what was wrong with me, then they had meetings, but they didn't have meetings with me involved in there, so I didn't really understand why I was there. But the medication, I don't know, I don't know what it was for.' (Kelly, BC) (Lawrence et al., 2021a)	No one explained anything Lack of patient involvement in decision making			
	Eric: 'I felt they should have counselled me.'; AC: 'You weren't getting counselling?'; Eric: 'Yeah...well they wouldn't give me counselling at all. They wouldn't give me counselling.'; AC: 'Were other patients getting counselling?'; Eric: 'Yes, yes, yeah.'; AC: 'Why do you think those patients were getting counselling and you weren't?'; Eric: 'Because I was my colour.' (Chakraborty et al., 2009)	Not being offered talking therapy due to ethnicity	The desire and preference for talking therapy		
	I probably would like to see if I could get to the bottom of why I have developed this illness. [PAC51, Interview with African Caribbean service user participant] (Rathod et al., 2010)	Desire to understand the cause of the illness			
	this context of difficult life circumstances was not taken into account in psychiatrists' evaluation of the patients' problems. They expressed frustration with the process of diagnosis and treatment, which was, in all cases, medication, with no "talking therapy" offered (Ally & Brennan, 2015)	Desire for talking therapy			
	Less money being put in treatment for Black people, of course there is, that's for sure. Who in this room has been offered, you know, talking therapy when they needed it at the beginning? (Focus Group 3) (Schofield et al., 2019)	Not being offered talking therapy due to ethnicity			
	Notably, those who felt overlooked by services (…) expressed the most frequent and severe forms of stigma and reported not having been offered psychological input (Vyas et al., 2021)	Lack of psychological input seen as reason for dissatisfaction towards services			
4	Jade: 'I think it's utter nonsense really...it really is... This time they felt they had to give me something. You see, by the time I got into hospital I was so scared of what was actually going on, it hit me then: "Oh no, I've been sectioned (legally detained in hospital), I'm in the mental hospital...somebody else is yet again in control of my life." It was like my whole life the control was in other people's hands all the time... My mind was over the fence...you know, it was like a process of reclaiming my mind once I arrived in here.' (Chakraborty et al., 2009)	Power held by the system not individual	Lack of choice and control over one's own care; dehumanising nature of services	Lack of Autonomy, Choice, and Individuality	Chakraborty et al., 2009, Rathod et al., 2010; Weich et al., 2010; Ally & Brennan, 2015; Islam et al., 2015; Wagstaff et al., 2018; Lawrence et al., 2021a
	Jade: 'I felt a bit let down actually 'cos he couldn't help me at all... All I really need is someone, one person, man or woman, I'm not particularly fussy, who listens to me...who I can come and talk to.' (Chakraborty et al., 2009)	All I need is someone who listens and I can talk to			
	A common theme by a majority of BME patients was that of being treated impersonally, as "a number". The following typifies this: If I'm going to tell you about myself, I want to know something about you [PAC1, Interview with African Caribbean service user] (Rathod et al., 2010)	Being treated impersonally			

	They do not give us a choice whether we want him to take the medication or not. You can ask them questions but you cannot tell them what to do. I think it is because they are in much more control. When you ask about the medication, for example, what it does and the side effects, they say that every medication has side effects, but they do not take into account what you are saying. They do not give us a proper explanation on how it is going to help him, the advantages and disadvantages; they do not really go into that deeply (Ally & Brennan, 2015)	Lack of choice regarding treatment No one explained anything			
	Why is it such a battle to get them to recognize what the parent is saying you know I was so angry, that's my child, I know my child" (C12, Carer, Black British-Caribbean, female) (Islam et al., 2015)	Feeling not listened to			
	well it's not my choice you know. I ain't got a choice because I got, if the mental health people come with me or come to give me medication, I take it, you know what I mean? But deep down I really don't want it. (Wagstaff et al., 2018)	Lack of choice regarding treatment			
	I used to communicate to them to say that I wouldn't like that, in other words, 'Don't give it me'. But they insist . . . I just seemed to drift away and just slumber (Wagstaff et al., 2018)	Feeling not listened to			
	Like many other participants, he felt that the power to decide whether he was ill resided with the mental health system, noting they 'do whatever's necessary to make you well in their eyes'. (Lawrence et al., 2021a)	Power held by the system not individual			
	the majority characterised receiving a diagnosis as something that was done to them by others and very few felt involved in this process (Lawrence et al., 2021a)	Lack of say in diagnosis process			
	'It was awful, there was very few people who actually cared in there, I mean to be in such an environment where people don't care, and they hold all the cards, and you have absolutely no rights and you have, you know, there's no respect, I mean it was...a nightmare'. (Ira, BC) (Lawrence et al., 2021a)	Environment with no care, rights, or respect			
	Participants vividly recalled their agitation and confusion and many criticised mental health professionals for failing to explain what was happening to them at a point when they were at their most vulnerable. Tessa (BC) explained that this sense of powerlessness had a lasting effect: 'From then I couldn't talk to anyone, I didn't feel I could trust any- one there, to be treated like that I just lost so much trust'. (Lawrence et al., 2021a)	No one explained anything Sense of powerlessness Loss of trust			
5	These are influenced by "shame" to the community, family and to the individual. In the South Asian Muslim group, maintaining "family honour" by hiding anything that would be perceived as "disgrace to the community or family" is paramount to patients who participated. People decline help from counsellors or therapists fearing that distress may be linked to the family gene, or may reveal issues that will impact not only on their family but community as a whole. Community views (e.g. gossip/rumours) from the grapevine are influential. (Rathod et al., 2010)	Shame of having mental health issues Pressure to maintain family honour	Mental health stigma amongst individuals and cultures further exacerbated by mental health service involvement	Stigma within Services and Society	Rathod et al., 2010; Islam et al., 2015; Wagstaff et al., 2018; Schofield et al., 2019; Lawrence et al., 2021b; Vyas et al., 2021
	No I didn't tell the church, I kept it secret from the church members, I didn't tell them. I don't think they would have understood (C14, Black British-Caribbean, female). (Islam et al., 2015)	Religious organisation would not have understood			
	I think for Asian people it's quite difficult having a mental health problem . . . Asian people aren't as accepting if you have a mental health problem and treat you very differently (SU7, British Pakistani, female). (Islam et al., 2015)	Mental health stigma amongst Asian communities			

	The participants described the stigma of mental illness and the stigma of involvement in mental health services as contributing to their isolation in society (Wagstaff et al., 2018)	Involvement with mental health services increases stigma			
	I think they think it's a stigma. I think African people, I think they find it hard to accept that there's mental health problems in their family. I think they find it hard to accept (Focus group 2) (Schofield et al., 2019)	Mental health stigma amongst African communities			
	I feel like with my family there was always that need to make sure everything looked good . . . If something came up about my mental health, my family wouldn't tell people which kind of made it worse . . . it's a lot about pride, family pride (Anwar). (Vyas et al., 2021)	Mental health stigma amongst Asian communities Pressure to maintain family honour			
	"I know when you're really scared about hearing voices, I just think automatically that everyone's going to think I'm crazy and like no one is going to talk to me. I won't be treated the same" (Aaliyah). (Vyas et al., 2021)	Others will think I'm crazy			
6	AC: 'How is their experience different?'; Eric: 'Because they know their backgrounds. They know where they're from, know how to cope with it, know how to use the resources they have, and things like that.'; AC: 'What's preventing you from knowing how to use all of the resources?'; Eric: 'Well I'm new here, you know?' (Chakraborty et al., 2009)	Individuals from BAME backgrounds have less resources	Shortage of resources due to immigration background; seeking help from faith healers; the significant support from families; stress management as an important coping strategy	Support and Resources Required for Recovery	Chakraborty et al., 2009; Penny et al., 2009, Rathod et al., 2010; Weich et al., 2010; Ally & Brennan, 2015; Islam et al., 2015; Schofield et al., 2019; Lawrence et al., 2021a; Lawrence et al., 2021b
	They were concerned by their family members' isolation. For example, Mrs. Saeed said, "I want him to have good company, because that's like medication." (Penny et al., 2009)	Reducing isolation as a form of treatment			
	The family was felt to be primarily responsible for the welfare of the young person. Mrs. Rehman's statement is typical: "I would do anything I can to help her, to get her back to where she was before. (Penny et al., 2009)	Significance of family support			
	African Caribbean participants reported a common practice of seeking help from faith healers. (Rathod et al., 2010)	Seeking help from faith healers was common			
	Mental illness is thus dealt with in the family or extended family. (Rathod et al., 2010)	Mental illness is dealt within the family			
	The influence of faith was predominantly seen as important by Muslim service users and those who cared for them. Despite not necessarily providing an explanation for their experiences, faith was seen as a source of support. (Weich et al., 2010)	Faith as a source of support			
	A17 (Pakistani female): The home treatment is really good—they can come in the house, they can get to know you, what sort of routine you have. Every person has a different... routines. Maybe the next person they see is on the same medication, but he doesn't have [a] special needs... child, who is not a single mother. So, every person needs individual home treatment. I am quite happy with, because they come and look at you, look at the environment you live in and look at the routine (Ally & Brennan, 2015)	Benefits of home environment			
	it should be arranged for the [Muslim] scholar and the psychiatrist to sit together and try to find a solution because they both help, so they might be able to find the cure (Ally & Brennan, 2015)	Psychiatrists should collaborate with religious scholars			
	Service user participants talked about the lack of choice in terms of gender of the professionals they came into regular contact with (i.e., care coordinators). However, for most service users, this was not a problem,	Lack of choice in choosing professionals'' characteristics was			

provided professionals had the relevant skills and expertise needed to fulfill their roles. Equally "ethnic matching" of professionals and users was not considered to be a priority, provided professionals acknowledged their culture and treated them with respect. (Islam et al., 2015)	mitigated by expertise, cultural acknowledgment and being treated with respect
The failure of general practitioners (GPs) listening to and addressing carers' concerns was also considered a key factor in delaying access to appropriate services by the majority of carers (Islam et al., 2015)	Failures of GP delayed access to care
We just don't have support systems. I mean my parents came here back in the 60s and they left their brothers and sisters behind. We didn't have the support system. (Focus Group 2) (Schofield et al., 2019)	Lack of support systems in UK due to immigration background
The biggest factor in this country, why most Black people are diagnosed, it is isolation because where we come from, massive families, with good friends, got relatives, we've aunties. But when you come here to this country you are alone in your house. (Focus Group 1) (Schofield et al., 2019)	Isolation as a result of being an immigrant

Appendix B
Detailed CASP Checklist

CASP Questions:

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

	Chakraborty et al. (2009)	**Penny et al. (2009)**	**Rathod et al. (2010)**	**Weich et al. (2010)**	**Ally & Brennan (2015)**	**Islam et al. (2015)**	**Wagstaff et al. (2018)**	**Schofield et al. (2019)**	**Lawrence et al. (2021a)**	**Lawrence et al. (2021b)**	**Vyas et al. (2021)**
Q1	Yes	Yes	Yes	Yes	Yes	Yes	Yes – although it should be noted that the aims were changed to focus on black men after the first four interviews	Yes	Yes	Yes	Yes
Q2	Yes - to explore subjective experiences	Yes - to explore subjective experiences	Yes - to explore subjective experiences	Yes - to explore subjective experiences	Yes - to explore subjective experiences	Yes - to explore subjective experiences	Yes - to explore subjective experiences	Yes - to explore subjective experiences	Yes - to explore subjective experiences	Yes - to explore subjective experiences	Yes - to explore subjective experiences
Q3	Yes - both qualitative and cross-sectional design explicitly justified	Yes - Qualitative design explicitly justified	Yes - Qualitative design explicitly justified	Yes - Qualitative design explicitly justified	Yes - Qualitative design explicitly justified	Yes - Qualitative design explicitly justified	Yes - Qualitative design explicitly justified	Yes - Qualitative design explicitly justified	Yes - Qualitative design explicitly justified	Yes - Qualitative design explicitly justified	Yes - Qualitative design explicitly justified
Q4	Partly - inclusion criteria and recruitment method were explained. - However, the aim stated that it was exploring	Yes - inclusion criteria and recruitment method were explained	Partly - inclusion criteria and recruitment method were explained - However, the two ethnic groups were	Yes - inclusion criteria and recruitment method were explained	Partly - inclusion criteria briefly stated. Recruitment method not explained.	Yes - inclusion criteria briefly stated. Recruitment method was detailed.	Yes - inclusion criteria and recruitment method were explained	Yes - inclusion criteria and recruitment method were explained	Yes - inclusion criteria explained. recruitment method briefly explained as being part of the AESOP-10 study	Yes - inclusion criteria explained. recruitment method briefly explained as being part of the AESOP-10 study	Yes - inclusion criteria and recruitment method were explained

	the experiences of "African-Caribbean" patients. However, the inclusion criteria specified "black people of Caribbean origin". This seems to exclude the experiences of black African patients and no justification was provided.		excluded from the study due to insignificant numbers and possibility of over-extending the study.								
Q5	Yes **Data collection method:** Ethnographic individual interviews – reasons not explicitly justified. **Data protection:** Interviews audio-taped and transcribed. No mention of encrypted devices or	Yes **Data collection method:** Individual semi-structured interviews. reasons explained. **Data protection:** Interviews recorded and transcribed by professional translator. No mention of encrypted devices or	Yes **Data collection method:** Individual interviews and focus groups – reasons explained **Data protection:** Interviews audio-recorded and transcribed. Field notes also taken to record non-verbal communication. Access to data was limited to	Yes **Data collection method:** Individual interviews - reasons not explicitly justified **Data protection:** Interviews audio-recorded and transcribed. No mention of encrypted devices or protection of data.	Yes **Data collection method:** Individual semi-structured interviews – reasons explained **Data protection:** Not stated **Interview schedule:** Not explicitly stated, but interviews were stated to be semi-structured.	Yes **Data collection method:** Focus groups - reasons not explicitly justified **Data protection:** Interviews audio-recorded and transcribed. No mention of encrypted devices or protection of data.	Yes **Data collection method:** Individual interviews – a main interview and a clarifying interview **Data protection:** Interviews audio-recorded and professionally transcribed. No mention of encrypted devices or	Yes **Data collection method:** Focus groups - reasons explained **Data protection:** Interviews audio-recorded and identifying data removed during transcription. No mention of encrypted devices or protection of data.	Yes **Data collection method:** Individual interviews – reasons explained **Data protection:** Interviews audio-recorded and transcribed. Participants were assured that interviews were confidential. No mention of encrypted devices or	Yes **Data collection method:** Individual interviews – reasons explained **Data protection:** Interviews audio-recorded and transcribed. Participants were assured that interviews were confidential. No mention of encrypted devices or	Yes **Data collection method:** Individual semi-structured interviews – reasons justified **Data protection:** Interviews audio-recorded and transcribed by first author. No mention of encrypted devices or protection of data.

	protection of data. **Interview schedule:** Not specified. Minimal structure to interview – reasons justified **Saturation of Data:** Not discussed	protection of data. **Interview schedule:** Used as a flexible guide. Design of schedule explained. **Saturation of Data:** Not discussed	research team. No mention of encrypted devices. **Interview schedule:** Interview guide themes listed **Saturation of Data:** Discussed	**Interview schedule:** Used as a flexible guide. Design of schedule explained. Additional question added after pilot interviews – reasons justified **Saturation of Data:** Discussed	Design of schedule not explained. **Saturation of Data:** Not discussed. Although the authors acknowledged the small sample size and lack of generalisability of the data.	**Interview schedule:** Used as a guide. Design of schedule explained. **Saturation of Data:** Not discussed	protection of data. **Interview schedule:** Not specified **Saturation of Data:** Not discussed	**Interview schedule:** Used as a flexible guide. Design of schedule not explained. **Saturation of Data:** Not discussed	protection of data. **Interview schedule:** Not explicitly stated, but implied it was used as a flexible guide. Design of schedule not explained. **Saturation of Data:** Not discussed	protection of data. **Interview schedule:** Not explicitly stated, but implied it was used as a flexible guide. Design of schedule explained **Saturation of Data:** Not discussed	**Interview schedule:** Used as a flexible guide. Design of schedule not explained. **Saturation of Data:** Not discussed
Q6	Partly - researcher's ethnicity and assumptions on how this could have influenced participants were briefly highlighted. However, no reflections on how it could have influenced the design of the study or data collection.	No	Yes - the influence of the researcher's identity on participants was considered. Bracketing and qualitative supervision was also used to reduce bias in data collection and interpretation.	No	No	No	Yes - Researcher mentions use of reflective diary and discussions with service user reviewers and project supervisor. The possible impact of the researcher's gender and ethnicity on participant's responses were briefly considered in the discussion.	No - groups were chaired by a BAME former service user. Impact of the facilitator on responses not discussed. Researcher's own bias and influence on analysis also not considered.	Yes - Interviewer's identity as a White male academic was mentioned. Strategies used to increase awareness of the researcher's influence and interpretations were also discussed. Researcher's own possible bias in the analysis was also	Yes - Interviewer's identity as a White male academic was mentioned. Strategies used to increase awareness of the researcher's influence, biases, and interpretations were also discussed.	Yes - The interviewer's (first author) and second author's identity were acknowledged and its impact briefly considered.

							However, the researcher's role, possible bias and influence in data collection and analysis were not explicitly discussed in the write-up.		briefly discussed in the discussion.		
Q7	Partly **Ethics approval:** Stated **Research explained to participants:** Through letter explaining purpose of study **Informed consent:** Partly - Only those agreed to participate were interviewed. However, it is unclear whether those contacted had provided consent to be contacted for research. Additionally, no	Partly **Ethics approval:** Stated **Research explained to participants:** Briefly stated **Informed consent:** Partly - Only those agreed to participate were interviewed. However, it is unclear whether those contacted had provided consent to be contacted for research. Additionally, no	Partly **Ethics approval:** Stated **Research explained to participants:** Not stated **Informed consent:** Yes. Written consent obtained before interviews. Consent was also obtained from the psychiatrist before contacting participants. **Confidentiality:** Pseudonyms used in write-up.	Partly **Ethics approval:** Stated **Research explained to participants:** Not stated **Informed consent:** Yes. Consent was obtained for service users to be contacted about research. Written consent obtained from participants. **Confidentiality:** Pseudonyms used in write-up **Impact on**	No **Ethics approval:** Not stated **Research explained to participants:** Not stated **Informed consent:** Not stated **Confidentiality:** Pseudonyms used in write-up **Impact on participants:** No mention of how this was addressed	Partly **Ethics approval:** Stated **Research explained to participants:** Yes, methods detailed **Informed consent:** Yes. Consent was obtained for service users and carers to be contacted about research. Consent was obtained from all participants prior to commencing the focus groups.	Partly **Ethics approval:** Stated **Research explained to participants:** Briefly implied, participants met with the researcher up to three times before the interviews. However, it was not explicitly stated that the research was explained to participants. **Informed consent:** Partly - Only those agreed to	Partly **Ethics approval:** Stated **Research explained to participants:** Yes, information sheet and purpose of study and implication explained to potential participants. **Informed consent:** Yes, research was advertised through posters and advertisements. Consent obtained from participants	Partly **Ethics approval:** Not explicitly stated. However, this research is embedded within the AESOP-10 study. **Research explained to participants:** Briefly stated **Informed consent:** Unclear whether participants gave consent to be approached for further research. Written informed consent was obtained from	Partly **Ethics approval:** Stated **Research explained to participants:** Briefly stated **Informed consent:** Unclear whether participants gave consent to be approached for further research. Written informed consent was obtained from participants prior to the interview. **Confidentiality:** Participants were assured the	Yes **Ethics approval:** Stated **Research explained to participants:** Yes, participants given information sheet **Informed consent:** Yes, informed consent obtained, and interested participants contacted the researcher directly. **Confidentiality:** Pseudonyms used in write-up

	mention of use of consent forms. **Confidentiality:** Pseudonyms used in write-up. **Impact on participants:** No mention of how this was addressed	mention of use of consent forms. **Confidentiality:** identifying information changed and pseudonyms used in write-up **Impact on participants:** No mention of how this was addressed	**Impact on participants:** No mention of how this was addressed	**participants:** No mention of how this was addressed		**Confidentiality:** Pseudonyms used in write-up **Impact on participants:** No mention of how this was addressed	participate were interviewed. However, it is unclear whether those contacted had provided consent to be contacted for research. Additionally, no mention of use of consent forms. **Confidentiality:** Unclear if pseudonyms were used. **Impact on participants:** No mention of how this was addressed	prior to focus groups. **Confidentiality:** Identifying information removed during transcription. **Impact on participants:** No mention of how this was addressed	participants prior to the interview. **Confidentiality:** Participants were assured the interviews would be confidential. No identifying information reported in the study. **Impact on participants:** No mention of how this was addressed	interviews would be confidential. Unclear if names used were pseudonyms. **Impact on participants:** No mention of how this was addressed	**Impact on participants:** Report mentions that participants were debriefed following the interview. Details were not provided.
Q8	Partly. Coding was explained in detail. A software was used to analyse the data, however it was unclear what type of qualitative	Partly Analysis process explained. Analysis checked in the form of audit - Analysis done by first author also checked by	Yes Analysis process explained. Themes were triangulated by being independently reviewed by three other researchers.	Partly Analysis process explained. Triangulation briefly discussed. Data was presented explaining each theme and subtheme.	Partly Analysis process only very briefly reported. No triangulation. Data was presented explaining each theme	Partly Analysis process explained. Analysis checked in the form of audit – categories coded into themes by first author and	Yes Analysis process explained. Analysis checked in the form of audit – clusters organised into themed through researcher's interpretations, discussions with	Partly Analysis process explained. Triangulation briefly discussed – data coded by two researchers Data was presented	Yes Analysis process explained. Triangulation briefly discussed – data analysed independently by two researchers Data was presented	Yes Analysis process explained. Triangulation briefly discussed – data analysed independently by two researchers Data was presented	Yes Analysis process explained. Triangulation briefly discussed – data analysed by two researchers Data was presented

	analysis was used. No triangulation Report states that the respondents described were chosen as their answers were 'typical' of their ethnic and gender groups. However, the extracts were not presented according to the coding categories and subcategories presented, making it unclear how those categories were derived. Researcher's own possible bias in the analysis not considered.	second and third author. Data was presented explaining each theme and subtheme. Findings "largely focused on commonalities" with contradictory data or differences "accommodated in the broader narrative" Researcher's own possible bias in the analysis not considered.	Data was presented explaining each theme and subtheme. Saturation of data briefly discussed. Researcher's own possible bias in the analysis was considered	Saturation of data discussed. Researcher's own possible bias in the analysis not considered.	Researcher's own possible bias in the analysis not considered.	checked by second author Data was presented explaining each theme Researcher's own possible bias in the analysis not considered	service user reviewers and discussions with supervisors Data was presented explaining each theme Reflective diary used throughout analysis process	explaining each theme Researcher's own possible bias in the analysis not considered	explaining each theme Researcher's own possible bias in the analysis was considered	explaining each theme Researcher's own possible bias in the analysis was considered	explaining each theme Researcher's own possible bias in the analysis was considered
Q9	Partly	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

	The findings presented do not clearly corelate with the coding categories and subcategories presented. Adequate discussion around findings provided. The credibility of the findings was not sufficiently discussed.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed briefly.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed.	The findings are explicit and clear. Adequate discussion around findings provided. The credibility of the findings was discussed.
Q10	Partly Impact of findings on current practice was considered. Areas for future research not considered.	Yes Impact of findings on current practice and research was considered.	Yes Impact of findings on current practice and research was considered.	Yes Impact of findings on current practice was considered. Areas for future research only considered very briefly.	Partly Impact of findings on current practice was considered. Areas for future research not considered.	Yes Impact of findings on current practice was considered. Areas for future research only considered very briefly.	Partly Impact of findings on current practice was considered. Areas for future research not considered.	Partly Impact of findings on current practice was considered. Areas for future research not considered.	Partly Impact of findings on current practice was considered. Areas for future research not considered.	Partly Impact of findings on current practice was considered. Areas for future research not considered.	Yes Impact of findings on current practice and research was considered.

Appendix C

List of Platforms and Organisations the Research was Advertised to

Social Media

Facebook – General

Facebook Group – Intervoice: The International Hearing Voices Movement

Facebook Group – Minorities in Clinical Psychology Group

Facebook Group – Asians in UK - AUK

Facebook Group – BAME Hub UK Network

Facebook Group – Voice Hearers World-wide

Facebook Group – Mad in the UK

Facebook Group – Nottingham Women's Centre

Facebook Group – BAME Mental health awareness

Twitter

LinkedIn

Instagram

Organisations*

The Black, African and Asian Therapy Network

CHARM - The Community for Holistic, Accessible, Rights Based Mental Health

BPS Psychotherapy Section

Voice Collective

Black Minds Matter UK

London Hearing Voices Network

Intervoice

Bristol Hearing Voices Group

Bromley Hearing Voices Group

Mind in Camden

National Paranoia Network

Friendship Group (Hearing Voices Network)

CPSL Mind

Oxfordshire Mind Hearing Voices Group

Waltham Forest Hearing Voices Group

Black Thrive Global

Mental Health Foundation

IRIE Mind

Manchester MIND

Hearing the Voice - Durham University

ISPS

Psychology Sussex Ltd

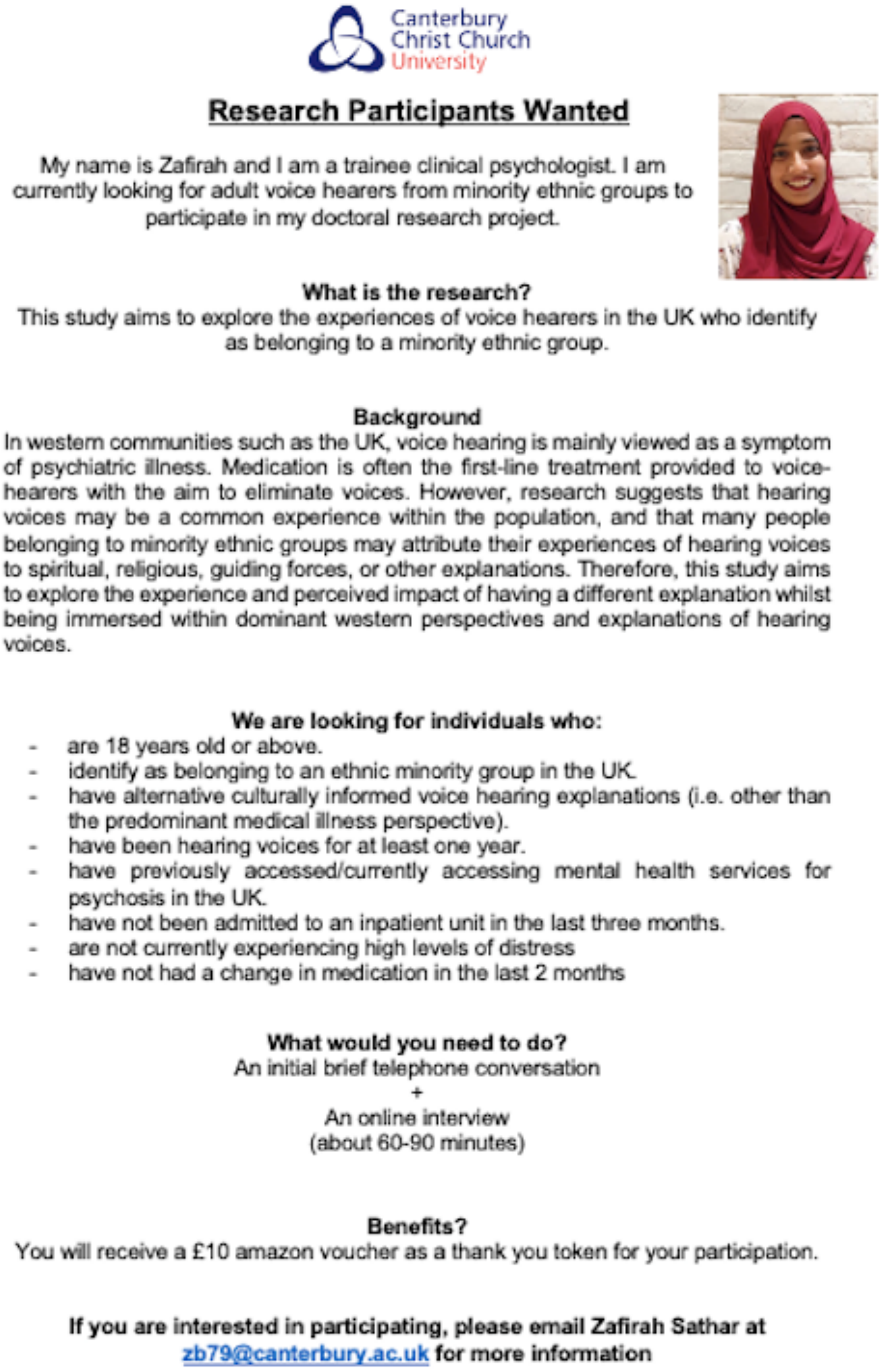
Muslim Counsellor and Psychotherapist Network

UK MAAC at Telford

Belfast Hearing Voices Group

* Only Organisations which replied to my email are listed

Appendix D
Research Advertisement Poster



Canterbury Christ Church University

Research Participants Wanted

My name is Zafirah and I am a trainee clinical psychologist. I am currently looking for adult voice hearers from minority ethnic groups to participate in my doctoral research project.

What is the research?

This study aims to explore the experiences of voice hearers in the UK who identify as belonging to a minority ethnic group.

Background

In western communities such as the UK, voice hearing is mainly viewed as a symptom of psychiatric illness. Medication is often the first-line treatment provided to voice-hearers with the aim to eliminate voices. However, research suggests that hearing voices may be a common experience within the population, and that many people belonging to minority ethnic groups may attribute their experiences of hearing voices to spiritual, religious, guiding forces, or other explanations. Therefore, this study aims to explore the experience and perceived impact of having a different explanation whilst being immersed within dominant western perspectives and explanations of hearing voices.

We are looking for individuals who:

- are 18 years old or above.
- identify as belonging to an ethnic minority group in the UK.
- have alternative culturally informed voice hearing explanations (i.e. other than the predominant medical illness perspective).
- have been hearing voices for at least one year.
- have previously accessed/currently accessing mental health services for psychosis in the UK.
- have not been admitted to an inpatient unit in the last three months.
- are not currently experiencing high levels of distress
- have not had a change in medication in the last 2 months

What would you need to do?

An initial brief telephone conversation
+
An online interview
(about 60-90 minutes)

Benefits?

You will receive a £10 amazon voucher as a thank you token for your participation.

If you are interested in participating, please email Zafirah Sathar at zb79@canterbury.ac.uk for more information

Appendix E
Participant Information Sheet

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Ethics approval number: ETH1920-0338
Version number: 2.0

Information about the research

Hearing Voices within a Western Society: From an Ethnic Minority Perspective
Name of Researcher: Noor Khatijah Zafirah Binti Abdul Sathar

Hello. My name is Zafirah Sathar and I am a Trainee Clinical Psychologist at Salomons Institute for Applied Psychology, Canterbury Christ Church University. I would like to invite you to take part in a research study.

This research is supervised by Dr Sue Holttum (Chartered Psychologist; Salomons Institute for Applied Psychology, Canterbury Christ Church University) and Dr Stephanie Phillips (Clinical Psychologist; NHS).

Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

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

Part 1:

What is the purpose of the study?
In western communities such as the UK, voice hearing is dominantly viewed as a symptom of psychiatric illness. Hence, medication is often the first-line of treatment provided to voice-hearers with the aim to eliminate voices. However, research suggests that hearing voices may be a common experience within the population, and that many individuals from minority ethnic groups may attribute their experiences of hearing voices to spiritual, religious, guiding forces, or other explanations. Therefore, this study aims to explore the experience and perceived impact of having a different explanation whilst being immersed within western-perspectives and explanations of hearing voices.

Why have I been invited?
You have been invited because you have shown interest to be a part of this study.

To be a participant in this research, you must:

- be 18 years old or above.
- identify as belonging to an ethnic minority group in the UK.
- have alternative culturally informed voice hearing explanations. Some common examples of other explanations are listed in the 'what is the purpose of the study' section.
- have been hearing voices for at least one year.
- have previously accessed/currently accessing mental health services for psychosis in the UK.
- confirm that you have not been admitted to an inpatient unit in the last three months.
- confirm that you are not currently experiencing high levels of distress
- have not had a change in your medication in the last 2 months

Do I have to take part?

- Taking part in this study is <u>entirely voluntary</u>, and you are free to make your own choice about whether you want to participate.
- If you agree to take part, I will then ask you to sign a consent form.
- Throughout the study, you can choose not to answer any questions that you do not want to, and you are free to withdraw at any time without giving a reason.

What will happen to me if I take part?

If you choose to take part in this study, you would have:

1. An initial short telephone conversation.
2. A main interview.

<u>Initial short telephone conversation:</u>

- During this call, you will have the opportunity to ask me any questions or raise any concerns you may have about this study.
- I would ask you a few basic questions about you and your experiences to check that you are eligible to take part in this study.
- As talking about your experiences in the interview may trigger feelings of discomfort and distress, I would also like to explore what support systems you may have available to you.

<u>Main interview:</u>

After the phone conversation, if you still choose to take part in this study:

- Depending on what you prefer, this interview may be conducted on the same day as the telephone conversation, or on a different day.
- The interview is expected to last about 60 to 90 minutes and will take place via a video conferencing platform at a time that suits you. This means that you will not have to travel to take part in this study and can choose a private and quiet place that is convenient for you. If you have any concerns about having an online interview, I am happy to discuss these with you.
- During the interview, I will ask you some questions related to your experiences of hearing voices and being a part of an ethnic minority group in the UK. It is important for you to remember that there are no right or wrong answers as I am interested in your experience and perspectives.
- I will record the audio of the interview as this will allow me to listen to it again later for transcription and analysis. The interview will be recorded using

a Dictaphone and will be transferred to a password protected memory stick immediately after the interview. There will be no identifying information that could link you to the audio recording. Any names and locations mentioned in the interview will be changed to preserve your anonymity.

Expenses and payments

After the interview, you will be emailed a £10 amazon voucher as a thank you token for your participation.

What are the possible disadvantages and risks of taking part?

Talking about your experiences may trigger feelings of discomfort and distress. If this occurs during the interview, please let me know as your wellbeing is important.

What are the possible benefits of taking part?

There are no clinical benefits to taking part in this study.
We cannot promise the study will help you, but we hope that the information we get from this study may help improve the future treatment provided by mental health services to people who hear voices.

What if there is a problem?

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

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

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

This completes part 1.

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

Part 2:

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

If you choose to withdraw from the study, all of your data will be deleted from our records, as long as you let me know within two weeks of taking part in the interview.

Concerns and Complaints

If you have a concern about any aspect of this study, you should ask to speak to me, and I will do my best to address your concerns. You can contact me by:

1. Leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me [Zafirah Sathar] and I will get back to you as soon as possible.
2. Emailing me at zb79@canterbury.ac.uk.

If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology (fergal.jones@canterbury.ac.uk).

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

All information which is collected from or about you during the course of the research will be kept strictly confidential.

- The audio recording of your interview will be typed up and the files will be encrypted and stored on a password-protected memory stick.
- Any potentially identifying details, including your name, will be removed.
- The interview information and recording will not be linked to any contact details that you provide and will be stored separately so you cannot be identified.
- The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else.
- Once the project is completed, the anonymised data will be stored by Salomons Institute of Applied Psychology on a password-protected CD in a locked cabinet for 10 years and then destroyed. I will also keep a copy of this anonymised data for 10 years where it will be stored on a password-protected memory stick.

What will happen to the results of the research study?

What you tell me will inform this study. I may use anonymised extracts from what you have told me in my doctorate research project, however, these would not identify you. The findings of the research may also be published in research journals or used in presentations. Again, the data will not be traceable back to you and you will not be identified. If you would like to be sent a summary of the findings, please let me know and we can arrange for this.

Who is sponsoring and funding the research?

Canterbury Christ Church University.

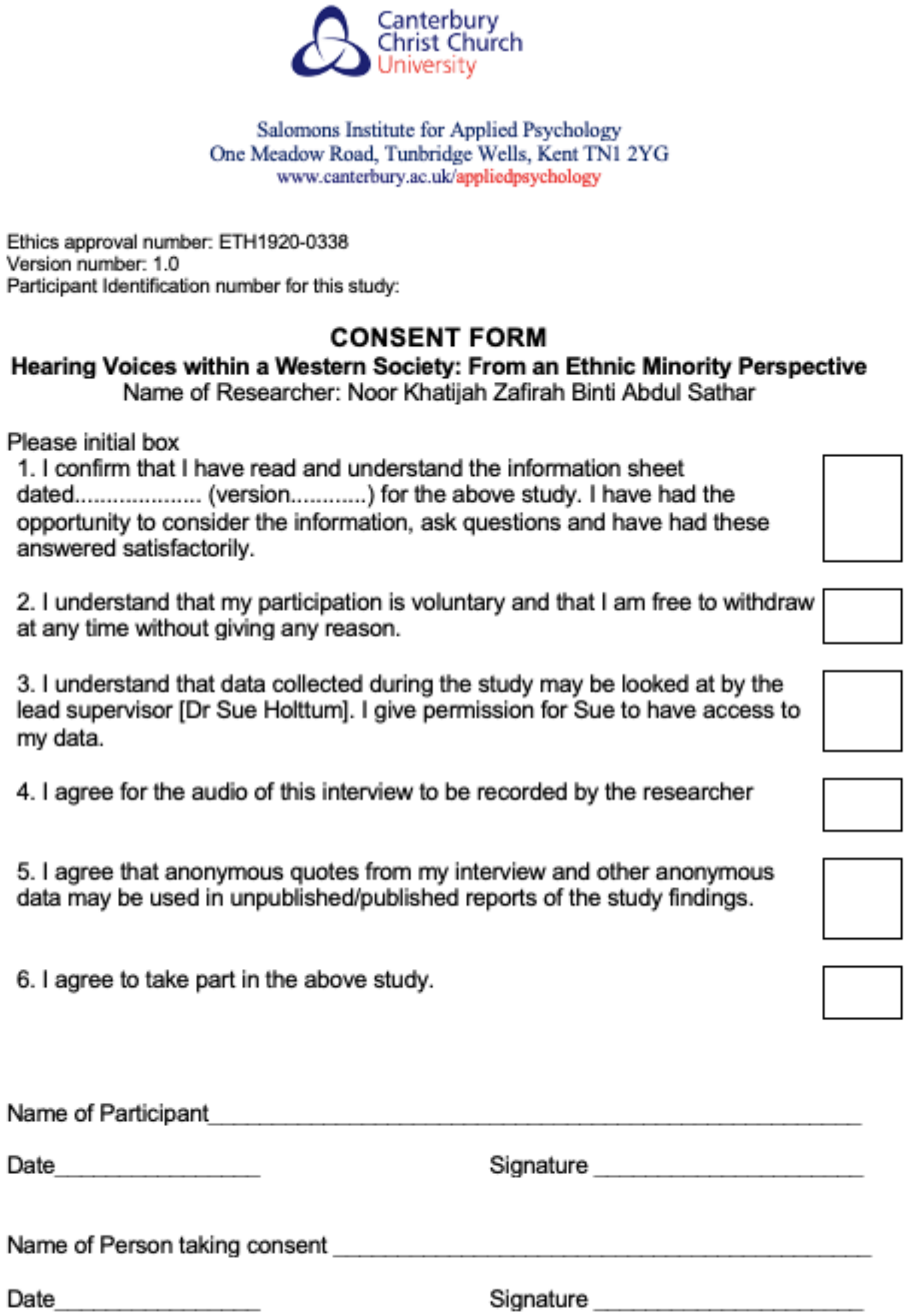
Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University [Ethics approval number: ETH1920-0338].

Further information and contact details

If you would like to speak to me and find out more about the study, or if you have questions about it, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me [Zafirah Sathar] and leave a contact number so that I can get back to you. Alternatively, you can email me at zb79@canterbury.ac.uk.

Appendix F
Consent Form



Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Ethics approval number: ETH1920-0338
Version number: 1.0
Participant Identification number for this study:

CONSENT FORM

Hearing Voices within a Western Society: From an Ethnic Minority Perspective

Name of Researcher: Noor Khatijah Zafirah Binti Abdul Sathar

Please initial box

1. I confirm that I have read and understand the information sheet dated.................... (version............) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I understand that data collected during the study may be looked at by the lead supervisor [Dr Sue Holttum]. I give permission for Sue to have access to my data. ☐
4. I agree for the audio of this interview to be recorded by the researcher ☐
5. I agree that anonymous quotes from my interview and other anonymous data may be used in unpublished/published reports of the study findings. ☐
6. I agree to take part in the above study. ☐

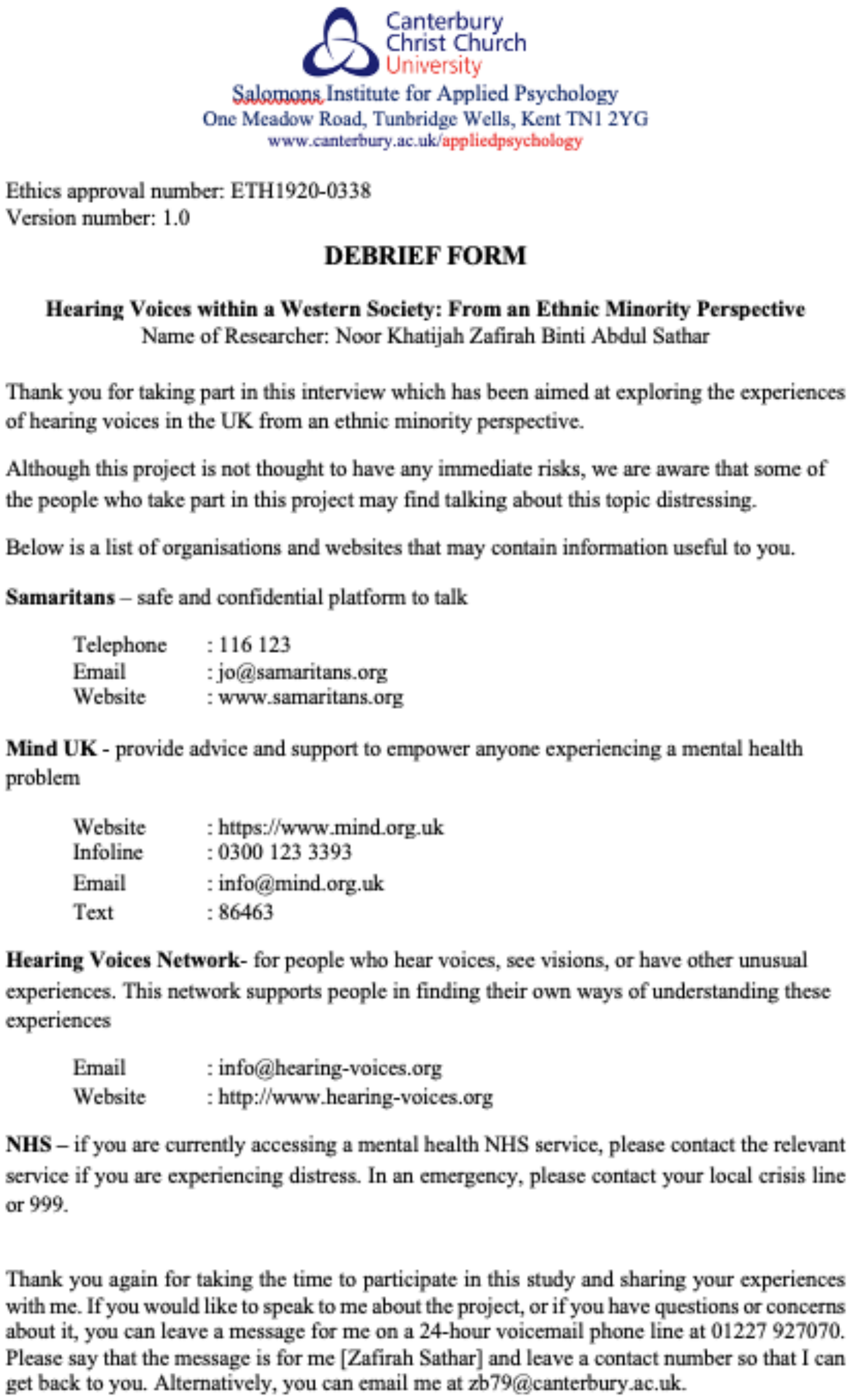
Name of Participant____

Date_________________ Signature ______________________

Name of Person taking consent _______________________________________

Date_________________ Signature ______________________

Appendix G
Debrief Sheet



Canterbury Christ Church University
Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Ethics approval number: ETH1920-0338
Version number: 1.0

DEBRIEF FORM

Hearing Voices within a Western Society: From an Ethnic Minority Perspective
Name of Researcher: Noor Khatijah Zafirah Binti Abdul Sathar

Thank you for taking part in this interview which has been aimed at exploring the experiences of hearing voices in the UK from an ethnic minority perspective.

Although this project is not thought to have any immediate risks, we are aware that some of the people who take part in this project may find talking about this topic distressing.

Below is a list of organisations and websites that may contain information useful to you.

Samaritans – safe and confidential platform to talk

Telephone : 116 123
Email : jo@samaritans.org
Website : www.samaritans.org

Mind UK - provide advice and support to empower anyone experiencing a mental health problem

Website : https://www.mind.org.uk
Infoline : 0300 123 3393
Email : info@mind.org.uk
Text : 86463

Hearing Voices Network- for people who hear voices, see visions, or have other unusual experiences. This network supports people in finding their own ways of understanding these experiences

Email : info@hearing-voices.org
Website : http://www.hearing-voices.org

NHS – if you are currently accessing a mental health NHS service, please contact the relevant service if you are experiencing distress. In an emergency, please contact your local crisis line or 999.

Thank you again for taking the time to participate in this study and sharing your experiences with me. If you would like to speak to me about the project, or if you have questions or concerns about it, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me [Zafirah Sathar] and leave a contact number so that I can get back to you. Alternatively, you can email me at zb79@canterbury.ac.uk.

Appendix H
Interview Schedule

Can you tell me a little about your family history and culture?

P: Were your parents born and raised in the UK?

P: Were you born and raised in the UK?

Could you tell me a little about your experiences of belonging to a minority ethnic group in the UK?

P: Have you ever experienced any form of discrimination?

How do people within your culture explain hearing voices?

How long have you been hearing voices?

When you first started hearing voices, how did you make sense of it?

P: Why did you think you were hearing these voices?

P: What were the voices saying, if you feel okay to tell me?

P: To what extent would you say your culture was able to help you make sense of the voices?

Can you tell me a little about your hearing voices journey?

P: (e.g. did you tell anyone, did you seek help, did you google your experiences)

P: Did your experience change over time? How?

P: What services have you accessed?

P: What treatment have you been offered?

P: How would you describe your experiences with the treatment offered?

P: How was your treatment pathway decided?

How did people around you react when they found out that you were hearing voices?

P: How did these reactions impact you and your experiences?

What explanations of hearing voices have you encountered in the UK?

P: How has your mental health professional explained hearing voices to you?

How do you feel about the explanation of voices (e.g. as above) emphasised in the UK?

P: How much do you agree or disagree with it?

P: How much do you think it explains your experiences?

P: Have you been prescribed medication? [if yes] what is your experience of this?

How do you feel about having multiple different explanations?

P: Do you connect more with one explanation over the other(s)? [if yes] Why?

P: Did the differences impact your relationship with your voices? [if yes] How?

P: Did this differences impact whether or not you sought help? [if yes] How?

How would you describe your relationship with your voices?

P: Has this changed over time? [if yes] How?

P: What do you think made it change?

Would your journey have been different if you were in a different country or society?

P: [if yes] How?

What helps you with your voices?

Is there anything you think I haven’t covered that you would like to add?

Do you have any questions for me?

Thank you very much for taking part in this study.

Appendix I

Summary report for Salomons Ethics Committee and Interview Participants

Hearing Voices within a Western Society from an Ethnic Minority Perspective: Navigating Explanations and Culture

Background

Research highlights existing ethnic inequalities in pathways into mental health care, and descriptions of the rigidity of the medical model which does not take cultural explanations and understanding into account. Moreover, current research suggests that navigating multiple cultural identities may also play a role in experiences of hearing voices.

Aim

The aim of this study was to explore ethnic minority voice-hearers' experiences of being immersed within and navigating Western society and explanations of hearing voices in the UK.

Method

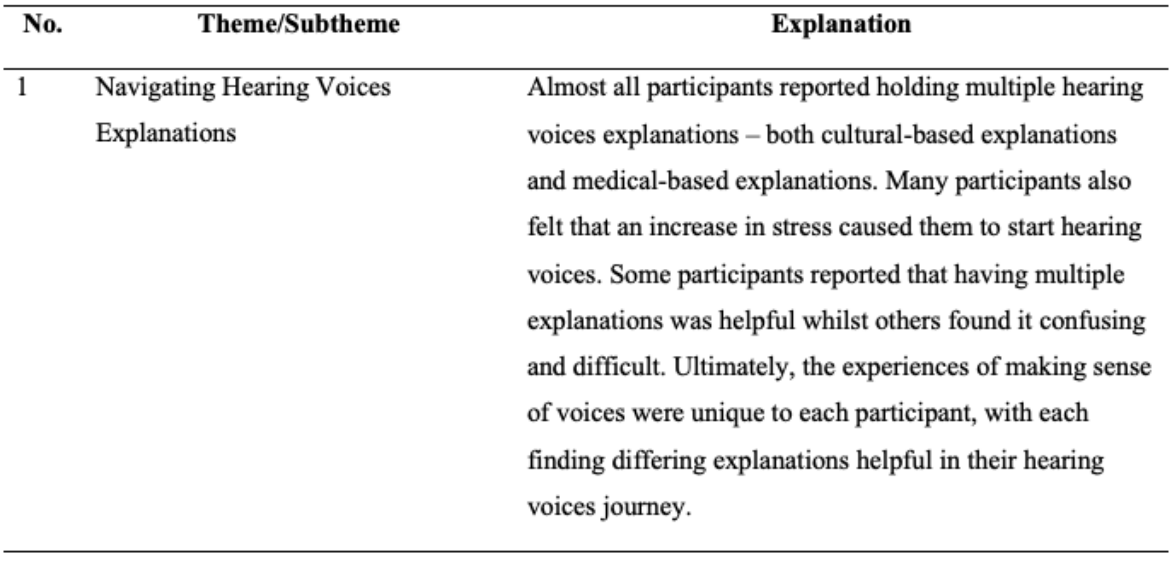
Individual semi-structured interviews and stories from published books were analysed using thematic analysis – four interviews and eight stories. Due to recruitment challenges, it was decided that the data from the four interviews would be complemented using mental health journey or recovery stories published in books.

Results

Six themes were developed as illustrated in Table 2.

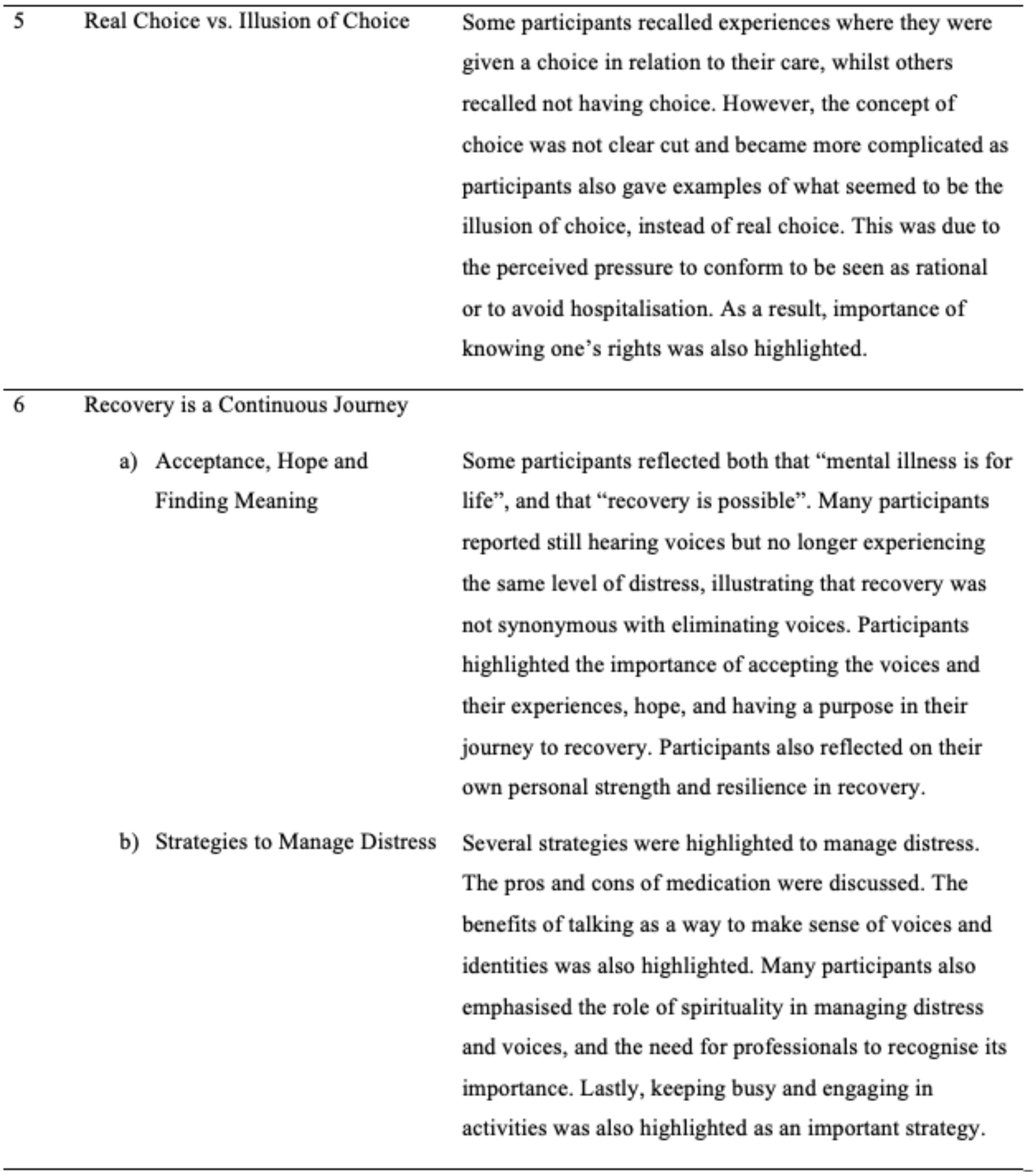
Table 2.

Summary of themes and subthemes



No.	Theme/Subtheme	Explanation
1	Navigating Hearing Voices Explanations	Almost all participants reported holding multiple hearing voices explanations – both cultural-based explanations and medical-based explanations. Many participants also felt that an increase in stress caused them to start hearing voices. Some participants reported that having multiple explanations was helpful whilst others found it confusing and difficult. Ultimately, the experiences of making sense of voices were unique to each participant, with each finding differing explanations helpful in their hearing voices journey.

2	Navigating Cultural Identities is Stressful	All participants held multiple cultural identities, and this was sometimes stressful, and made participants feel as if they did not belong. Some participants linked this to the start of their hearing voices experience.
3	Hearing Voices within Current Society	
	a) Stigma and Discrimination	Participants highlighted the stigma associated to hearing voices in the UK, and consequently their apprehension in sharing their experiences with others.
	b) UK vs. Different Country/Culture	Participants highlighted the differences in how mental health, hearing voices, and diagnostic labels are perceived within various cultures, illustrating both the advantages and disadvantage of the British culture and other cultures.
	c) Helpful and Unhelpful Experiences with Services	There were mixed views around the helpfulness of mental health services, with many reporting both positive and negative experiences. Positive experiences were reported when people felt that they were being listened to and understood. Conversely, negative experiences centred around feeling unsupported, uncared for, and a lack of compassion.
4	Labels - Forceful and Powerful	Participants highlighted their experiences in receiving a schizophrenia or psychosis diagnosis, with many participants describing the lack of choice in this matter. Many participants also reported believing these diagnoses meant they were “insane”, “mad”, and “crazy”, illustrating the power labels can carry. Many participants felt they did not deserve the label, especially at the beginning of their experiences. The powerlessness in this aspect understandably then contributed to added distress and confusion, and may have also acted as a barrier to seeking help.



5	Real Choice vs. Illusion of Choice	Some participants recalled experiences where they were given a choice in relation to their care, whilst others recalled not having choice. However, the concept of choice was not clear cut and became more complicated as participants also gave examples of what seemed to be the illusion of choice, instead of real choice. This was due to the perceived pressure to conform to be seen as rational or to avoid hospitalisation. As a result, importance of knowing one's rights was also highlighted.
6	Recovery is a Continuous Journey	
	a) Acceptance, Hope and Finding Meaning	Some participants reflected both that "mental illness is for life", and that "recovery is possible". Many participants reported still hearing voices but no longer experiencing the same level of distress, illustrating that recovery was not synonymous with eliminating voices. Participants highlighted the importance of accepting the voices and their experiences, hope, and having a purpose in their journey to recovery. Participants also reflected on their own personal strength and resilience in recovery.
	b) Strategies to Manage Distress	Several strategies were highlighted to manage distress. The pros and cons of medication were discussed. The benefits of talking as a way to make sense of voices and identities was also highlighted. Many participants also emphasised the role of spirituality in managing distress and voices, and the need for professionals to recognise its importance. Lastly, keeping busy and engaging in activities was also highlighted as an important strategy.

Clinical Recommendations

- It may be beneficial for professionals to be more flexible in their practice and meaningfully acknowledge and respond to individuals' beliefs about their hearing voices experiences, and support voice-hearers to build a more positive relationship with their voices.
- It is important for mental health professionals to ensure individuals are given adequate information and choice about what is happening, diagnosis, and their treatment options, to enable them to make an informed decision.

- There is no one specific treatment option or strategy that helped all the participants. Hence, the care and options offered to voice hearers should be individualised and tailored to their needs, taking into account their wants, goals and hope for the future, and ultimately voice hearers should be the one to make the decision about their care.
- Considering the additional stressors faced by individuals from ethnic minority groups, and the possible risk of retraumatisation, it is important that mental health professionals and services keep in mind and acknowledge the possible impact of racism on people's lives and experiences, and incorporate the principles of trauma informed care in their practices.
- It is also important to explore individuals' cultural identities and the importance of this in relation to ethnic minority voice-hearers' experiences.

Zafirah Sathar
Trainee Clinical Psychologist
Salomons Institute for Applied Psychology

Appendix J
Confirmation of Ethics Approval from Salomons

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Appendix K

List of Final Codes Related to the Research Questions and Example Quotes

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Appendix L
Example of Interview Transcript with Final Codes

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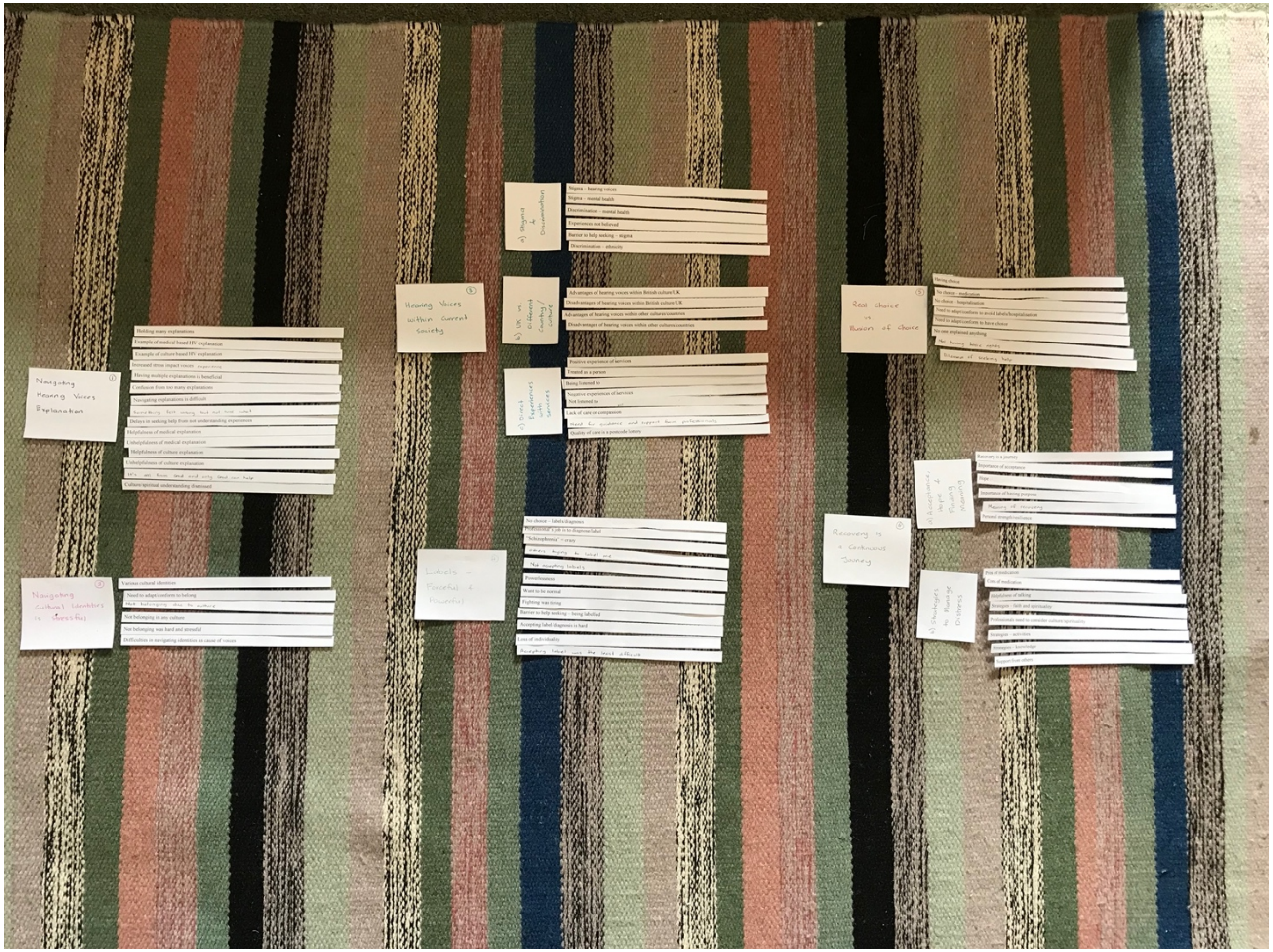
Appendix M

Themes, Subthemes and Codes



No.	Themes	Subthemes	Codes
1	Navigating Hearing Voices Explanations	-	Holding many explanations
			Example of medical based HV explanation
			Example of culture based HV explanation
			Increased stress impact voices experiences
			Having multiple explanations is beneficial
			Confusion from too many explanations
			Navigating explanations is difficult
			Something felt wrong but not sure what
			Delays in seeking help – not understanding experiences
			Helpfulness of medical explanation
			Unhelpfulness of medical explanation
			Helpfulness of culture explanation
			Unhelpfulness of culture explanation
			Culture/spirituality understanding dismissed
			It's all from God and only God can help
2	Navigating Cultural Identities is Stressful	-	Various cultural identities
			Need to adapt/conform to belong
			Not belonging due to culture
			Not belonging in any culture
			Not belonging was hard and stressful
			Difficulties in navigating identities as cause of voices

3	Hearing Voices within Current Society	Stigma and Discrimination	Stigma – hearing voices
			Stigma – mental health
			Experiences not believed
			Discrimination- mental health
			Barrier to seeking help – stigma
			Discrimination – ethnicity
		UK vs. Another Country/Culture	Advantages of hearing voices within British culture/UK
			Disadvantages of hearing voices within British culture/UK
			Advantages of hearing voices within other cultures/countries
			Disadvantages of hearing voices within other cultures/countries
		Direct Experiences of Services	Positive experiences of services
			Being listened to
			Treated as a person
			Negative experiences of services
			Lack of care or compassion
			Not listened to
			Need for guidance and support from professionals
			Quality of care is a postcode lottery
4	Labels – Forceful and Powerful	-	No choice – labels/diagnosis
			Professional's job is to diagnose/label
			"Schizophrenia" = crazy

			Others trying to label me
			Not accepting labels
			Powerlessness
			Want to be normal
			Everyone against me
			Fighting was tiring
			Barrier to help seeking – being labelled
			Accepting label/diagnosis is hard
			Loss of individuality
			Accepting label was the least difficult
5	Real Choice vs. The Illusion of Choice	-	Having Choice
			No choice – hospitalisation
			No choice – medication
			Need to adapt/conform to have choice
			Need to adapt/conform to avoid labels/hospitalisation
			Dilemma of seeking help
			No one explained anything
			Not having basic rights
			Knowing one's rights
6	Recovery is a Continuous Journey	Components of Recovery	Recovery is a journey
			Meaning of recovery
			Importance of acceptance

			Hope
			Importance of having purpose
			Personal strength/resilience
		Strategies to Manage Distress	Pros of medication
			Cons of medication
			Helpfulness of talking
			Need professionals to talk to
			Strategies – faith and spirituality
			Religious/cultural practices of managing voices
			Professionals need to consider culture/spirituality
			Strategies – knowledge
			Strategies – activities
			Support from others

Appendix N
Abridged Reflexive Journal

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Appendix O

Author Guidelines for Submission to the Journal of Cross-Cultural Psychology

Aims and Scope

Journal of Cross-Cultural Psychology **publishes papers that focus on the interrelations between culture and psychological processes. Submitted manuscripts may report results from either cross-cultural comparative research or single culture studies.**

Research that concerns the ways in which culture, and related concepts such as ethnicity, affects the thinking and behavior of individuals, as well as how individual thought and behavior define and reflect aspects of culture are appropriate for the ***Journal of Cross-Cultural Psychology*****.**

Cultural Variables. Cultural variables that may be related to the behavior(s) of interest should be assessedrather than relying upon conjectures regarding assumed cultural differences that could be influencing behavior(s).

Empirical Research. Most papers published in the *Journal of Cross-Cultural Psychology* are reports of empirical research. Empirical studies must be described in sufficient detail to be potentially replicable.

- **NOTE:** The *Journal of Cross-Cultural Psychology* does not publish psychometric studies of test construction or validation. Studies that compare scale performance or factor structure among different cultural groups are also not considered by the *Journal of Cross-Cultural Psychology*.

Reviews and Theoretical Papers. Integrative reviews that synthesize empirical studies and innovative reformulations of cross-cultural theory will also be considered. These reviews are expected to reformulate or offer a novel perspective to an existing cross-cultural theory or research area.

Single Nation/Culture Research. Studies reporting data from within a single nation should focus on cultural factors and explore the theoretical or applied relevance of the findings from a broad cross-cultural perspective.

Methods. Psychology publishes studies using quantitative, qualitative, and mixed methods.

Authors who are uncertain about the appropriateness of particular manuscripts should contact the Editor, Senior Editor, or any of the Associate Editors for clarification and advice.

Manuscript Submission Guidelines:

Journal of Cross-Cultural Psychology (*JCCP*) publishes material in three categories: (1) regular, unsolicited manuscripts, (2) brief reports, and (3) special issues. Summary details of each category are as follows:

1.Regular, Unsolicited Manuscripts. This is *JCCP*'s main emphasis. See Aims and Scope for a detailed description of appropriate manuscripts.

Manuscripts should be submitted electronically to http://mc.manuscriptcentral.com/jccp. Authors will be required to set up an online account on the SageTrack system powered by ScholarOne. Manuscripts will be sent out anonymously for editorial evaluation. Obtaining permission for any quoted or reprinted material that requires permission is the responsibility of the author. Submission of a manuscript implies commitment to publish in the journal. Authors submitting manuscripts to the journal should not simultaneously submit them to another journal, nor should manuscripts have been published elsewhere in substantially similar form or with substantially similar content. Authors in doubt about what constitutes prior publication should consult the Editor.

Manuscript length should normally be 15 to 35 double-spaced, typewritten pages. Longer papers will be considered and published if they meet the above criteria. Manuscripts should be prepared according to the most recent edition of the American Psychological Association Publication Manual. Manuscripts are reviewed by the Editorial Advisory Board. Allow up to 3 months for a publication decision and up to 1 year for publication.

2. Brief Reports. Accepted Brief Reports should be no more than 10 double-spaced manuscript pages long, including title page, references and any tables.

3. Special Issues. An important part of *JCCP*'s publication policy is the periodic publication of special issues or special sections of regular issues. Current needs, emerging trends, and readership interest guide the publication of material in this category. Ideas or suggestions for special issues or special sections should be discussed with Walter J. Lonner (Walter.Lonner@wwu.edu), Founding and Special Issues Editor, or other members of the Editorial Advisory Board, especially current Editor, Deborah L. Best (best@wfu.edu).

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