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'Like I said about culture. You don't talk about mental health': An interpretative phenomenological analysis of the experience of first-episode psychosis in South Asian individuals

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Abstract

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

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

Results: Three superordinate themes were identified in the group analysis: (1) Disconnection from self and others (2) Doubt and dispute (3) Power and shame.

Conclusions: Distinctive ethnic, cultural and systemic influences were strongly evident in how people conceptualized their experiences, how they managed their sense-making and where they sought support. Experiences were discussed in the context of power and shame, and this research proposes that socio-cultural context and racialised discourses have an impact on self-concept, the experiences of help-seeking (formal and informal), and fundamentally *how* services help individuals from marginalized communities.

KEYWORDS
first-episode psychosis, interpretative phenomenological analysis (IPA), south Asian

1 | INTRODUCTION

There is robust evidence of inequalities in mental healthcare access (Anderson et al., 2014; Morgan et al., 2005), experiences of service users (Prajapati & Liebling, 2021) and outcomes across different ethnic groups (Drake et al., 2020; Marshall et al., 2005; Ran et al., 2015). To address this, numerous policy frameworks and government guidelines encourage health services to provide 'culturally-competent' person-centred care. However, the translation of policy into race equity in services remains an area of contention (Salway et al., 2016). Related to this, it can be argued that although broader conceptualisations of 'psychosis' are emerging, including consideration of cultural—identity, —conceptualisation of distress, and—features of the relationships with healthcare professionals (HCPs; ICD-11: World Health Organization, 2019; DSM-5: American Psychiatric Association, 2013), the clinical utility of these remains challenging. Currently, ICD-10 (World Health Organization, 2016) and the DSM-5 (American Psychiatric Association, 2013) frameworks, based on a Eurocentric medical model, remain internationally prevalent (Reed et al., 2019).

Unpicking culture-specific lived experience and associated language of these phenomena is one way to help identify the limits of current thinking and inform the ways in which our thinking can develop, with a move towards the decolonisation of mental health (MH) (Hernández-Wolfe, 2011; Lucero, 2011). Decolonisation in its broadest sense refers to equity of resources, equalizing power and privilege and challenging the assumptions institutions are based on (Fay, 2018). Although research has begun to speculate about cultural variation in the experience and conceptualisation of psychosis (Saleem et al., 2019), little research has been conducted in the South Asian (SA) community, despite this population constituting the second largest ethnic minority group in the United Kingdom (Office of National Statistics, 2011).

The Indian subcontinent of southern Asia is comprised of the following: Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan and Sri Lanka. In the United Kingdom, approximately 5.2% of the total population identified as 'South Asian' (Office of National Statistics, 2011). Ongoing immigration has led to Pakistan and India being amongst the top three most common countries of origin for UK migrants in 2019 (Rienzo & Vargas-Silva, 2020). Given that these communities represent a large population in the United Kingdom, and for continuity and comparison across research, this study will use the term South Asian to pertain to the following countries: Bangladesh, India and Pakistan.

However, there is a category fallacy in the term South Asian, in that it does not constitute a homogenous group of people: there is a very high degree of religious, linguistic, cultural and economic heterogeneity in this population. It is also important to acknowledge that culture is a fluid concept and not static. It is influenced by surrounding cultures, and is not the only salient framework by which people define themselves. In a similar vein, 'ethnicity', 'ethnic group' or 'ethnic identity' are descriptive terms that are often used interchangeably. They may be used for identification by others and for individuals to self-identify. Although ethnicity is often used interchangeably with race and culture, these are separate constructs that are intertwined. In this study, race was also considered in the context of power, dominance and subjugation.

Epidemiological evidence suggests that rates of psychosis are disproportionately higher in ethnic minority and migrant groups in the United Kingdom, particularly those of African-Caribbean and SA heritage (Jongsma et al., 2019; Kirkbride et al., 2012; Kirkbride et al., 2017; Saleem et al., 2019). A recent study exploring first episode psychosis (FEP) incidence rates (per 100 000 person-years) in the United Kingdom found increased rates in Bangladeshi (39.08) and Pakistani (33.58) individuals compared to White other (21.46) and White British (19.52) groups (McDonald et al., 2021). Interestingly, the incidence rate appeared lower in people of Indian ethnicity, compared to other ethnic groups (Beattie et al., 2020; McDonald et al., 2021), suggesting differences between and within ethnic minority populations.

In the United Kingdom, Early Intervention Services in Psychosis (EIS) have been implemented. However, research suggests that SA service users are more likely to present later to EIS services (Beattie et al., 2020; Iyer et al., 2010), miss outpatient appointments (Agius et al., 2010), have fewer primary care contacts during the 6 months prior to their diagnosis of psychosis (Kline & Thomas, 2018) and are three times more likely to demonstrate treatment attrition (Quellet-Plamondon et al., 2015).

Qualitative studies exploring the experience of psychosis in SA service users in the United Kingdom have reported shame, stigma, discrimination and social and structural barriers impeding help-seeking (Connor et al., 2016). Additionally, illness experiences have been reported to influence participation and interaction with the wider SA community (Virdee et al., 2017). In their systematic review, Prajapati and Liebling (2021) noted overall themes of SA service users feeling distanced from services, experiencing dilemmas of trust and a threat to their cultural identity. Those studies exploring illness beliefs have reported that SA service users often understand MH illness in the context of spiritual/religious frameworks for example punishment from God, witchcraft, spirits and black magic and psychosocial factors (e.g., stress or drug use; Bhikha et al., 2015; McCabe & Priebe, 2004; Virdee et al., 2017; Weatherhead & Daiches, 2010). Notably, participants have reported that they felt that, although clinicians were open to hearing alternative perspectives, they did not actively provide any intervention in line with these ways of understanding (Virdee et al., 2017). Perhaps as a result, pluralistic intervention appears to be a common approach for this population (Bhikha et al., 2015; Dein & Sembhi, 2001; Weatherhead & Daiches, 2010).

Overall, research suggests there is variation in the epidemiology, service access and engagement and recovery for those belonging to a SA ethnic minority group. However, methodological limitations and underrepresentation of this group in samples restricts drawing firm conclusions. Qualitative work in this community suggests there are several intersecting cultural factors that need to be given further consideration in this population. However current research is limited by heterogenous samples, including mixed ethnic groups (Connor et al., 2016) and heterogenous MH illness experiences and countries of origin (Dein & Sembhi, 2001; Weatherhead & Daiches, 2010) or a focus on a single cultural dimension (Dein & Sembhi, 2001).

Furthermore, it appears that explanatory models are not mutually exclusive, multiple explanations can be held simultaneously, and treatment within this population can be pluralistic. However, relatively little is known about the broad experience of FEP in British SA and if and how different explanatory models interact with each other to influence help-seeking, illness experiences and recovery. It appears that whilst our knowledge of alternative illness explanations is increasing, this has not been translated into improvements in access to care and outcomes for SA service user's (Fitzpatrick et al., 2014). To address this issue, an exploratory study was conducted focussing on how British SA individuals make sense of their experiences of FEP, within the context of a particular cultural and service delivery setting. This would allow for exploration of an experience from the position of the person, and moves beyond making comparisons based on category membership.

A broad research question was explored: How do South Asian individuals experience and make sense of psychosis? The aim of this study was to demonstrate existence rather than incidence (Smith et al., 2009) and show us that or how something *is*. As such, participants were encouraged to (re)interpret their lived experience and reflect on the conditions that surrounded their psychotic experience in reference to past events and histories, and also in the context of their social-cultural framework.

2 | METHOD

2.1 | Approach

An IPA approach was adopted in this study. The central aims of IPA are twofold: to obtain an 'insider's perspective' of the phenomena under study via listening closely to the experiences described by the individual experiencing them (idiographic) and to attempt to interpret the accounts in order to gain an understanding of what sense people have made of their experiences within their particular context (phenomenological and interpretative; Larkin et al., 2006).

This research was conducted in line with the Code of Human Research Ethics (British Psychological Society, 2018).

Ethical approval was obtained from Yorkshire & The Humber—South Yorkshire Research Ethics Committee [REF: 20/YH/0153]. Written and/or verbal (audio recorded) informed consent was obtained from all participants prior to their participation. All participants have been given a pseudonym.

2.2 | Sampling

Within the IPA approach, it is stipulated that the sample should consist of a homogenous set of participants who have lived experience of the phenomena being explored, whilst avoiding 'identikit' participants (Smith et al., 2009). This is to allow for a degree of convergence and divergence in individual accounts and the development of shared sense-making of experiences. Due to its idiographic nature and in-depth analysis of individual cases and experiences, relatively small sample sizes are deemed appropriate for IPA research designs.

With this in mind, the study used purposive sampling (see Table 1. for inclusion criteria). No exclusion criteria were applied regarding participants' migration status (e.g., those seeking asylum, 1st generation, 2nd generation etc.). Inclusion was regardless of gender, sexual orientation or disability and other protected characteristics. All participants were recruited from an EIS, in the United Kingdom.

TABLE 1 Inclusion criteria

1	18 years of age or older
2	Capacity to provide informed consent (as assessed by gatekeeper involved in their care).
3	Experience of first episode psychosis.
4	Able to engage in an interview about their experience with psychosis e.g., not currently experiencing features of florid psychosis.
5	South Asian ethnicity, from three broad self-ascribed ethnic groups: Bangladeshi, Indian and Pakistani.
6	Able to converse in English (as determined by gatekeeper).
7	Would not be at risk of becoming significantly distressed if they took part in the study (based on the clinical judgement of gatekeeper involved in their care).

2.3 | Participants

The sample consisted of eight participants. Seven participants self-ascribed as British Pakistani and one as British Bangladeshi. There were three men, four women, and one non-binary participant, between the ages of 19 and 40, with a mean age of 25.9 (*SD* = 8.07). Participants had been with EIS for between 1 and 3 years at the time of their interview(s). Five participants had a diagnosis of First Episode Psychosis. One participant had a diagnosis of Schizoaffective disorder, one had Bipolar affective disorder, and one had Paranoid schizophrenia. All participants reported being born in the United Kingdom and reported parents had immigrated to the United Kingdom 15+ years ago.

2.4 | Semi-structured interview

A semi-structured topic guide (available on request) was developed in an iterative manner in consultation with academic colleagues working in the field of psychosis, clinical colleagues in EIS and service user consultants (Hearing Voices group and Help from Experts by Experience for Researchers (HEER) group). Both groups consisted of a diverse group of individuals, including ethnicity and mental health experiences. Open-ended, exploratory questions were used to invite the participant to talk about their experience (e.g., 'I'm interested to hear about your first experience of noticing something out of the ordinary, maybe feeling different, or something unusual happening. Can you tell me about it…?').

Based on a strong recommendation from the HEER group all participants were offered a second (follow-up) interview to take place approximately 1 week after interview 1. This was to ensure that a complete narrative was captured regarding the participants experiences, and the participant was given the time to reflect on the interview topics discussed. Six of the eight participants consented for a second interview, of which five participants attended. Two participants declined the offer of a second interview, and one participant had consented to be contacted for a second interview but was not reachable. Individual interviews (one and two) lasted between 12 and 120 min each. On average interview 1 lasted approximately 75 min and interview 2 approximately 35 minutes. All interviews were audio recorded and transcribed in full.

2.5 | Data analysis

The general process of analysis in IPA has been described extensively (Smith et al., 2009). The process is broadly inductive, and develops iteratively and collaboratively through a series of stages, that are utilized flexibly, in order to identify patterns of meaning (themes) in the data (see Table 2. for analysis process).

3 | RESULTS

Three major themes were identified during cross-case analysis of the data: (1) disconnection from self and others; (2) doubt and dispute and (3) power and shame (see Table 3). These themes reflect the participants' experiences and the meaning they have made of them, the journey of meaning-making and their experiences in context. The super-ordinate themes were endorsed by all participants, with varying degrees of convergence and divergence of the sub-ordinate themes within their individual narratives.

3.1 | Disconnection from self and others

3.1.1 | A terrifying and uninvited intrusion and something about me has changed

Participants characterized their experiences as a sense of disconnection from self and from those around them. In some cases, disconnection appeared to be deliberate and operated as a protective mechanism to help buffer against rejection and avoid social stigma associated with mental health difficulties. Nazreen here reflects on the difficulty of defining her experiences to self and to others leading to her sense of disconnection:

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

TABLE 2 The process of data analysis in IPA

Stages	Process	
Reflection and immersion	Post-interview reflections were revisited at the start of the analysis process for each participant. Each transcript was initially read whilst listening to the audio recording to re-immerse in the data. Each transcript was then reread and notes were taken of initial impressions. A summary statement for each participant was written to inform a pen portrait.	First Author
Reflection and preparation	Theoretical assertions, personal values and the interviewers position as a British born Indian were reflected on with second and third authors, an IPA consultant and SA cultural consultant, with an attempt to ‘bridle’.	All authors, IPA consultant and SA cultural consultant
Experiential coding	Systematic line-by-line analysis of each separate dialogue, coding for descriptive, linguistic and conceptual components. Each transcript was divided into three columns: (1) raw data; (2) exploratory comments; and (3) emergent themes. To categorize emergent themes in the raw data, comments were colour coded.	First author in consultation with second and third
Integrative and interpretive coding	Higher order coding was synthesized, and emerging patterns were summarized for each participant using a thematic map.	First author in consultation with second and third
Organization	A document was developed for each participant containing codes and supporting quotes clustered under sub-ordinate themes. Super-ordinate themes for single cases were identified.	First author in consultation with second and third
Thematic development	Analysis developed from finalized single case analysis to multiple cases, where cross-case analysis of emergent themes was conducted. At this stage, areas of convergence and divergence in each person's account were recorded. Subordinate themes across multiple cases were identified and then analysed to identify superordinate categories that captured these themes.	First author in consultation with second, third and SA cultural consultant
Thematic structure	A summary of super- and sub- ordinate themes was developed, with relevant quotations and references within the text.	All authors

Abbreviation: IPA, interpretative phenomenological analysis.

TABLE 3 Super-ordinate and sub-ordinate themes identified

Superordinate theme	Subordinate theme	Quotes[a]
Disconnection from self and others	A terrifying and uninvited intrusion	I think it manifests itself like in life you have to be alone and you cannot connect with people. […] it's totally put me out of the family. I'm not that, I'm not allowed to be in the family anymore (Dalil) The most terrifying experience (Sophia) I did not know what was going on … and umm, I felt just like scared, actually scared as well things like something is going to happen to me. (Sirah)
	Something about me has changed	Yes, I think that the first thing that happened was losing touch with reality. Em that was the biggest thing that happened. I did not feel like I was here and I also did not feel like the people around me mattered or … I did not think that they cared about me or they were doing something like to hurt me? (Nazreen) I just thought I must be crazy. (Amina) And made me someone like who's not really a normal person, if that makes sense. (Dalil) You just feel different from everyone else and you just feel secluded, isolated in the way you think; and er, sometimes when you are trying to get your point across people do not understand what you are talking about (Ismail)
Doubt and dispute	Points on a journey towards understanding	They do not mean anything to me … I wished this never happened … I do not know where it come from, I do not know where it crept from. (Ismail) I dunno. It's just, there's something unexplainable, to be honest (Dalil) I feel like they all linked like the psychosis came along with a lot of depression, anxiety. I think it started off with depression because em … I did actually go onto some tablets, Fluoxetine, I think it was called? And em I think it all stemmed from depression and anxiety. Em I've always been quite an anxious person. And I think the psychosis actually came from that, because my an, my anxiety fears built up. It just built up so much that I just could not handle it anymore and I think that's what happened. I just lost control. And that's what I mean when I said I lost touch with reality. (Nazreen)
	Working with multiple explanations	It's just I feel I'm just sort of spiralling out of control in some way. Like they are trying to take over my life and I do not know who to turn to or what to turn to. I do not know who can make this problem go away, of hearing voices. (Dalil) He contacted a spiritual healer because what happened is um, er, obviously he was gonna seek the help of the professionals first. That was just an option because, it's just a option because they sorted of suggested it, you know home, back home in Pakistan they said, 'Well try everything. Even contact a spiritual healer if you have to, to get some answers' because um, they thought probably there's some dark entity, witchcraft or black magic that's on her. She's probably drank something from Pakistan that's affected her head. (Sophia) I thought like, I thought it might be evil eye and I was thought I was stressed at the same time. So, both things stress and evil eye. That's what I thought it was and it was that kind of, yeah, I think that's what triggered my psychosis as well just thinking that work, work, work. (Sirah)
	Testing and proof	And I've told him about the experience with Jinns. Sometimes he was there! When I, like when the Jinns were there and he'd like feel it as well. So that's how I knew it wasn't always erm … psychosis or something else. I knew part of it was real. Part of it, yeah, is real. (Asim) P: Em and em … yeah but it wasn't that cos we did get it checked. I: What do you mean? P: You can go to someone to get it checked like a religious scholar. I: Okay. **P: But that's ruled out cos obviously it wasn't that.** (Nazreen) I: did you have much contact with the general community **P: I did, yeah. I had contact with the local Imam and stuff like that and I told them, but they said it was black magic** (Dalil)
	Feeling resigned and overwhelmed	I just got used to it slowly and you know sometimes I can make the voices go away myself, I feel like I can but sometimes I cannot. When my mood is low then I just cannot. Then when the voices are there, they make me cry. (Amina) I do not know what they mean um … I do not know [mumbles] I really do not know… umm … I do not know. It's just insane; this is insane. (Ismail) I dunno. It's just, there's something unexplainable, to be honest. (Dalil)
	A battle for identity	So, basically, I was in autopilot mode so I wasn't really discussing, like I wasn't sitting with anyone and saying I need to tell them how I feel so I can, I just pushed it and just left it. And, because I got so good at faking it until you are making it, kind of thing, like I could not tell if I'd actually made it to the other side or I got so, I'd perfected it so well that um, I could just

(Continues)

TABLE 3 (Continued)

Superordinate theme	Subordinate theme	Quotes[a]
		get up and someone new would come. I'd just sit and talk, all confident. And, I never thought about it. (Salma) I find, I find that very offensive, because at the end of the day we live in England and it's dominated by English people so, we should want to be like English people and strive to be like them and be the same as how they are and the way they live and eat. And that should be our way of life because we are in their country end of day. (Dalil)
Power and Shame	Feeling empowered	It was different; it was very enlightening in some way because in some ways it was like doing something good for me by telling me things. And other ways it was kind of scary because I did not know where the voices were coming from or whose they were. (Dalil) I do not know … em that I knew I could talk, I had like a special power to talk to people. That's how I felt at the time. Like in my head! Yeah I do not know. I just thought I was some spiritual thing! So. But that wasn't it. It was just a hallucination. At the time I did not know what hallucinations were! I just thought oh I'm a genius. I can talk to people in my head or whatever! But … yeah. Basically. (Nazreen)
	Feeling disempowered	I felt comfortable talking to them but there was always a backlash; there was always something where they wanted to pin me down … after … yeah, pin me in a way like because I've got unconventional way of looking at it at that time th-e-y, they really wanted, they did not like it so. (Ismail) I had self-harmed really bad like, and it would not stop and I thought I was gonna die so I rang my sister and I was like can you please take me to the hospital and she was like 'no you cannot go. What's mum gonna say, what's dad gonna say'. So that's why I never, after that I never did tell anyone about how I felt or even if I self-harmed I just kept it to myself. (Amina) So, and plus, it would've been like if my father, with him being the head of the family. If he said I believe you, everybody would've rushed. (Salma)
	Hiding and being hidden	And even though they see all the signs, it's like they turn a blind eye to it. It's one of those things, and if you push it under the carpet it's gone, kind of thing. And that's how it's always been. So, but with my family it's always been the case with that, with anything. So, it's not just mental health issues or um, anything like that. (Salma) Our reputation. 'What are people gonna say?'(Amina) No. So for example extended family erm … so my … erm … my second cousins? They did not know. They still do not know a thing about my mental health! They do not even know that I've been struggling with depression because it's frowned upon to talk about! That's just! That's fucked like!. (Asim)

Note: P: refers to participant; I: refers to interviewer.

[a] All names have been anonymised.

3.2 | Doubt and dispute

3.2.1 | Points on a journey towards understanding

Doubt and dispute resonated across individual accounts, regarding the experiences themselves, the stage of understanding participants appeared to be in (i.e., searching, in the thick of it, reflecting back), within the context of working with multiple explanations and the recursive process of testing and identifying proof for their beliefs. For most participants there appeared to be a sense of resignation in the persistent internal conflict of identifying what is real and not. Often this led to seeking external advice; however, this interpersonal dimension of establishing a truth generated its own sense of mistrust in not only their own appreciation of what's going on, but the intentions of others:

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

3.2.2 | Working with multiple explanations

All participants described a default explanation for experiences, relating to a cultural/spiritual/religious understanding (e.g., 'Taweez',[1] Izzat,[2] Nazar,[3] Jinns[4]) and a health framework (e.g., FEP, psychosis) in the context of its provision from services.

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

> else. I knew part of it was real. Part of it, yeah, is real. (Asim)

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

> well, what I thought was happening was nothing related to mental health … it was more related to taweez [black magic] … you know basically, there was this man that er, in that same time of because of how I connected it to that, was the same time when the voices started, I had an altercation with a religious spiritual leader. (Salma)

> P: And my Mum thought it could have, well the thing is my Mum was in the middle as well! Like me! She thought it could be the spiritual or it could be, like we call it nazar.
>
> I: Can you tell me a bit more about that?
>
> P: Yeah. It's em basically when em someone, well in my religion we believe that when someone is jealous of you or they don't … they don't really like, yeah basically if they're jealous of you and they … they envy you. Em it can actually cause something like called nazar. And that's when something bad happens to you. Because of someone else's jealousy. So we do, that's what we believe. (Nazreen)

Participants discussed their sense-making of their experiences in the context of three sources: the self, family and community, and formal services (see Figure 1). Explanations were dynamic and fluid and for each individual the influence of each source varied; although all demonstrated a temporal quality and recursive process in developing an understanding. Although there was some level of a shared understanding between the self and other sources, there was little overlap between family/community sense-making and formal services sense-making. Only one participant appeared to accommodate and assimilate explanatory models into a system of beliefs (Sirah).

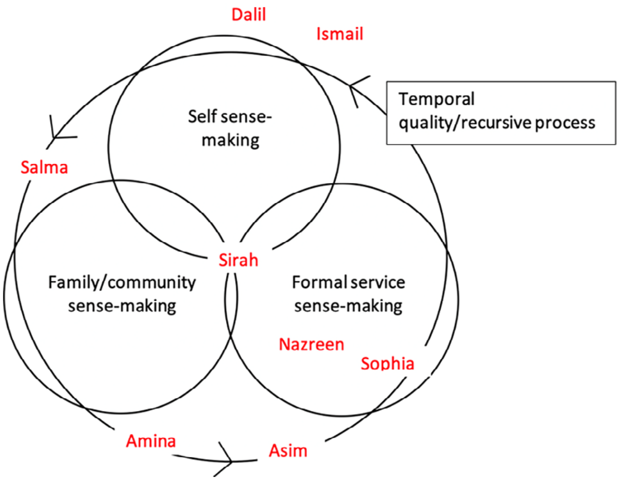

FIGURE 1 An illustration of the process of sense-making for participants

Whilst some participants described contemplating explanations (e.g., the intent of the voices, unusual beliefs), others reported multiple explanations created conflict and competition. There seemed an unhelpful tension of two seemingly opposing explanations, and distress and confusion stemming from the attempt to reconcile them. For example:

> So, it's like when, when I wasn't in a situation that was religious, if I wasn't praying, and the stuff that was happening, what I was getting told from here [gesturing around to EIS team building], that was making sense […] but when I was doing something in regards to reciting something or praying, that made sense. So, I was like stuck in between. So, it was like, like when I'm doing this, this makes sense. When I'm doing this, this makes sense because when I'm doing this then that doesn‘t make sense [gesturing using both hands as a scale] (Salma)

3.2.3 | Testing and proof

This tension led some participants to reject one explanation in favour of another, typically the spiritual explanatory model was rejected. This was often described in the context of managing confusion, avoiding shame and negative connotations associated with spiritual explanations and the power in the professional voice to define experiences. All participants sought external validation from family and community, including Imams or religious scholars/leaders/healers. Some participants spoke of performing rituals (Sophia, Sirah, Salma, Nazreen) that could identify proof of their spiritual explanatory framework:

> Even contact a spiritual healer if you have to, to get some answers' because um, they thought probably there's some dark entity, witchcraft or black magic that's on her. She's probably drank something from Pakistan that's affected her head (Sophia)

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

For Salma, within her spiritual explanation, MH difficulties were preventative and curable, and perhaps this also served to strengthen her conviction in it. Here, Salma reflects on the perceived inefficacy of the antipsychotic medication and efficacy of the ritual in stopping her voices:

> P: so, from where I was concerned, it was like the medicine, what it's supposed to do, it's not doing it. Cause I got put on Aripiprazole that was supposed to stop the voices but even though I was taking it, it wasn't, it was still there
>
> I: mm. And how long after the ritual did you realise you couldn't hear the voices anymore?
>
> P: Just straightaway! Soon as he did it. Once he'd done the whole, the pen thing on the feet. Once he'd done that, because once I'd come back to my own senses (Salma)

3.3 | Power and shame

3.3.1 | Feeling empowered and disempowered

Some participants recalled feeling empowered by their perceptual anomalies and this being challenged most acutely when those around them did not share this or labelled it as part of an illness. Disempowerment resonated strongly across accounts, as part of the unusual experiences themselves, in the context of belonging to the wider SA community and help-seeking (both formal and informal). For example, where power had been assigned to the professional voice, this appeared to be at the expense of their own. In interactions with the wider SA community, disempowerment was discussed in the context of feeling belittled, unheard and dismissed; along with the impact of being in restrictive family environments and the pressure to adhere to cultural norms, such as izzat.

> Erm yeah so. I, the male side of the culture. It's like you know you've got to be, you've got to be strong. You've got to be honourable. You've got to respect your family. Erm … You've always, you've got to be the confident person. You've got to be in charge. Erm … can't really show weakness when it comes to … mental capacity. And you can't have erm … yeah you can't be vulnerable in that sense. Yeah. (Dalil)
>
> and er, they're going to talk and er, basically I have brought shame on the family and I shouldn't be telling anyone … you know, 'If she's hearing voices why doesn't she just stay at home in the house; why doesn't she stay indoors and not interact with anyone (Sirah)
>
> Our reputation. 'What are people gonna say?' (Amina)

3.3.2 | Hiding and being hidden

Closely linked to this was secrecy and hiding things from others (including in interactions with EIS), or being hidden from others, such as extended family and the wider community. The detrimental impact of this on one's sense of identity was shared by all participants. For example, in the context of struggling to find belonging across two different cultures (host and heritage), and the impact of this on help-seeking. Prominent in this theme was the need to avoid risk of shame and social stigma associated not only with MH difficulties, but also more broadly (e.g., being in a relationship, drugs/alcohol use).

> Yeah. So you can't, you can't mention, for example you can't talk about weed! And you can't. So when you're talking about your issues you can't tell them everything. You can't say I'm using weed to … fight everything that's going on. I'm using it as a coping mechanism. You can't tell your father, you can't tell your parents that! Erm because … well … it's frowned upon in your culture. It's frowned upon in your religion. It's both in that situation […] No! Like I said about culture. You don't talk about mental health. (Asim)

4 | DISCUSSION

This study used IPA to consider how SA individuals experience and make sense of FEP. The unfamiliarity of the experience, difficulty recognizing signs (by self and others), denying there was a problem or anticipating that problems would recede naturally seemed to impede help-seeking and illustrated that some individuals (and those around them) needed to develop a sense of 'illness' before seeking help or accessing support. Participants described being unaware of psychosis and services and the language surrounding it, and reported that this was common across their community. A finding reflected in other reports exploring SA experiences of accessing MH support (Prajapati & Liebling, 2021). Overall, the absence of the term psychosis, associated language (e.g., paranoia) and the social construction of illness suggests there are cultural differences in the meaning and values assigned to what may have traditionally been referred to as 'symptoms' under a Eurocentric model. In light of this, cultural sensitivity would involve being aware that psychosis is constructed, communicated and understood differently in the SA community and that contact with formal services may include the external imposition of meaning.

Some themes identified in this study resonate with those reported in McCarthy-Jones et al. (2013) and Hansen et al. (2018) systematic reviews of studies conducted in majority White samples. Furthermore, in line with other IPA investigations into the experience of psychosis which reported themes related to the role of the voice and relationships with voice (Rácz et al., 2017) and emotional responses to extraordinary ideas and beliefs, such as fear, uncertainty and loss of control, loss of identity and adjustment (Todd et al., 2010) participants in this study also identified similar experiences. Overall, this suggests there are phenomenological overlaps in the experiences of psychosis between ethnic groups. However, this study's findings also diverge from these reports and Eurocentric conceptualisations on several counts, including, but not limited to culture specific content of the experiences (e.g., Salma seeing a churel,[6] Asim and others hearing, sensing or seeing Jinns); the degree of family involvement; paternalistic influences; the power of the community; the impact of bicultural identity, racism, discrimination and social exclusion (from indigenous and host cultures). This suggests that although there are commonalities in the experience of FEP, the complexity of the cultural context is a strong influence.

This study identified a culture-specific interpersonal dimension to disconnection. It appeared to be both an unintentional consequence of the experience, and also a deliberate attempt to help manage shame/stigma and mitigate the risk of *permanent* stigmatizing labels and becoming ‘part of the rumour mill’—reported to have a significant impact on social standing and community relationships. One explanation here is that for SA individuals, the family, more than the individual, is the key component of a social unit. They may have a more socio-centric self-concept, which privileges relationality, which may find itself at odds with an egocentric self-concept privileged in the current Eurocentric healthcare system (Langa & Gone, 2020). This study suggests that services need to give further consideration to working with a collectivist culture.

Distinctive cultural influence was perhaps most strongly evident in how people conceptualized their experiences, how they managed their sense-making and where they sought support for it. Participants in this study recalled initially holding a spiritual explanation for their experiences (such as ‘nazar’, ‘taweez’, ‘Jinns’, ‘black magic’ or ‘possession’), indicating this was a default belief and one not initially in line with a Eurocentric, biomedical conceptualisation of FEP. It is possible that having an indigenous label and/or explanatory model acted as a protective factor from internalized and experienced forms of stigma. For example, for some participants, spiritual explanations were associated with attribution to a malicious external force rather than a personal deficit or failure. However, it appears that interaction with EIS meant socialization to that service's model of understanding, and to the language that the service uses to describe psychosis experiences. It seems as though un/knowingly services are imposing definitions and explanations, that are not fully considerate of cultural norms and beliefs. Our study findings suggest EIS, can play a more proactive role in engaging in wider dissemination of different conceptualisations of psychosis, beyond the models they are most aware of, (e.g., via leaflets, posters, information on websites) to highlight its contested, rather than definitive nature or set up groups where individuals can meet and explore multiple beliefs. This may help promote a more collaborative, holistic approach to understanding and supporting SA individuals experiencing FEP.

In line with previous research (Bhikha et al., 2012; Bhikha et al., 2015; Carter et al., 2017; Dutta et al., 2019), this study also found that individuals came to hold multiple explanations for their experiences. This study demonstrates that SA individuals' personal explanatory models related to their ethnicity or culture may intersect with more dominant Eurocentric models used in services, and that they cannot be easily integrated, so that people are challenged with navigating multiple models. Echoing Islam et al. (2015) this study also found that SA service users were reticent about sharing their spiritual explanations with EIS staff due to a sense of embarrassment associated with this model, not feeling they would be believed or understood, or feeling that sharing this explanation would be associated with being ‘unwell’ and having ‘poor insight’. Interestingly, some participants recalled not sharing their explanatory model because they were not asked and spoke of the impact of not having a shared ethnicity with their HCPs. Ethnic matching between service users and HCPs has been reported to be both helpful and a hinderance (Prajapati & Liebling, 2021), and further research is needed to explore this.

Incongruence in illness belief models may have a significant impact on perceived insight in psychosis. Psychoses are often characterized by ‘poor insight’, where the individual holds a different interpretation of what is happening from that held ‘true’ by the culture in which they sit. If the dominant clinical language is not taking an individual's culture/experiences into account, it might make it more difficult for staff to understand the phenomena they are encountering and engage with service users' belief systems. Alternative conceptualisations may be mislabelled as poor insight and serve to devalue the service user's perspective. In this context, insight relates to acceptance of a dominant service model, a culturally constructed explanation of experiences that individuals must subscribe to. This may lead to cognitive dissonance and serve to endanger the therapeutic relationship and engagement with services.

4.1 | Implications

Despite the challenging condition EIS teams are operating within, it is clear that they are trying hard to uphold high standards of care. Participants described positive experiences of being cared for, advocacy and understanding. However, resonating with the wider BAME literature (Akther et al., 2019; Newbigging & Ridley, 2018), feeling disempowered was a salient experience for all participants. EIS may need to give further consideration to how the needs of SA individuals experiencing FEP are different, and make adaptations to engage better with the community they serve. This may involve using skilled outreach workers and providing high quality training (by those with lived experience and/or professionals) to other institutions (e.g., police, religious institutions) in working with MH difficulties and approaching vulnerable groups in different communities. Services may increase choice of how people access the service (e.g., home/clinic/outside of immediate area) and who they are seen by (e.g., preferences related to gender, ethnicity or religion). Given the current workforce diversity issues in the NHS in general healthcare and mental healthcare—including clinical psychology—this may not always be feasible, but where possible should be offered. There is a pressing need for increasing ethnic and cultural diversity of clinical psychologists and wider mental healthcare staff to adequately represent the population it serves.

Similar to other reports (Dutta et al., 2019; Saleem et al., 2019; Shah et al., 2019), participants in the study spoke of pluralistic help-seeking approaches that were often independent of each other, for example, prayer *or* medication. When considering appropriate intervention for minority groups, it is important to consider where the evidence for models and intervention comes from, who it is based on and crucially who is marginalized (see https://edisgroup.org/). This study highlights the need for clinicians to increase their awareness and work in collaboration with those providing cultural and religious interventions. This could be done by developing strong community links with trusted religious or community figures to develop a mutual understanding of MH and help-seeking and adapt service provision to different communities (Agius et al., 2010). Where psychological therapies have been adapted to work with presentations of psychosis, such as CBTp (Naeem et al., 2016), and in ethnic minority groups (Habib et al., 2015; Naeem et al., 2015), there is a risk that they minimize the lived realities of multiply marginalized service users. Further research is required exploring how interventions are adopted and whether there are further approaches that might be useful. For example, Mir et al. (2015) has developed culturally adapted behavioural activation for the treatment of depression in Muslims, involving a values assessment, and if religion is an important value provision of a booklet with for example Muslim religious texts as part of the therapy.

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

Acculturation has been reported to be associated with improved quality of life in BAME service users experiencing schizophrenia (de Mamani et al., 2017); however it is also the responsibility of the host service to design a system that meets their needs. Accessing support from a system that was not designed to meet the needs of SA individuals may also be contributing to a sense of threat to cultural identity and could increase the risk of associating more strongly with an illness identity (Cicero et al., 2016). Societal stigma has been consistently associated with BAME groups where there is more than one episode of psychosis (Islam et al., 2015; Loganathan & Murthy, 2011) and identified in IPA investigations exploring psychosis (Knight et al., 2003). However, this study demonstrates that the impact of stigma on one's social capital in the SA community can be rapid and immediate, even for those experiencing FEP and entering services for the first time. In light of this, services need to consider how to support SA service users, without exacerbating loss of social network and mirroring distressing experiences of intrusiveness. Beyond the risk of ‘double-stigma’ (Gary, 2005), there appears a risk of ‘multiple-stigmas’ associated with ethnicity and race, social standing and MH difficulties. For bicultural individuals, services should consider providing information about resources in the context of both the culture of origin and the host culture. For the former, this may include considering the benefits of cultural maintenance, and engaging with the community's traditions and practices, and for the latter it may mean providing transparent and accessible information about navigating the mental healthcare system. For both, co-production with service users, their family and community is highly encouraged (for e.g., bidirectional education). This may help to promote a sense of agency and empowerment, encourage social inclusion and help address the loneliness that appears to come with the experience of FEP in SA individuals.

Policy and service planning and delivery can play a key role in addressing this and wider disparities that exist between the service provision to White majority and marginalized groups. An initial action could be to prioritize the lived experience as informative in decision-making processes. This means acknowledging that the experience of MH difficulties and sense-making is impacted by intersecting identities including race, ethnicity and cultural identity. A consequence is that there is no one-size fits all conceptualisation of distress and therefore MH provision. Policies need to address the fragmented provision of healthcare across services and how this puts marginalized groups disproportionately at risk of ‘falling through the cracks’. Furthermore, policies need to be re-evaluated to examine if they truly address the structural inequalities at service level, and if and how these policies are being translated to race equity in local services (Salway et al., 2016).

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

The findings of this study highlight the role of commonly held group values in the SA community, such as collectivist emphasis, cultural codes such as ‵izzat′, pluralistic help-seeking and religious and cultural beliefs and explanatory models. However, they also suggest diversity and nuance in the lived experience. The findings further demonstrate the significant role of the socio-political structures in place that contribute to distress and perpetuate underutilisation of services by marginalized groups, due to inequitable healthcare and institutional racism. They highlight that services have a long way to go in addressing cultural exclusion, including poor service provision for those not belonging to the majority White population and poor acknowledgement of specific needs, such as those related to ethnicity and culture (Fernando & Keating, 2008). It is time to reconsider the historical label of 'hard to reach' applied to marginalized groups, and consider that it is the mental healthcare system that is *hard to reach*.

4.2 | Limitations

Conclusions drawn from the findings of this study must be interpreted in the context of the following methodological considerations. It is possible that there was a bias in who was selected by the gatekeepers and who agreed to take part in the study, which may impact the research's credibility. Study criteria may inadvertently perpetuate the idea that SA individuals form a homogenous group of people, just as many policies and services, within the NHS and beyond, refer to 'BAME groups' collectively. This may serve to problematically imply that all non-White groups have the same needs and are impacted by structural discrimination and racism in the same way. This study also stipulated an exclusionary criteria of non-English speakers—this served to exclude those individuals where English may not be their first language or people who may not be confident in conversing in English. This decision was based on the study methodology (IPA). However, by doing this the voices of others may have also been excluded (e.g., those with refugee or asylum-seeking status). By not taking into account the experiences of SA individuals who do not communicate fluently in English, this study may reflect wider inequalities and inequities to care present in services for these groups. However, despite these limitations, this does not invalidate the accounts of the participants who did take part.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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ENDNOTES

[1] Taweez refers to black magic and witchcraft.

[2] Izzat refers to honour/reputation within the family and wider SA community.

[3] Nazar refers to evil eye.

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

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

[6] Salma translated churel to "witch" for clarification.

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Additional supporting information can be found online in the Supporting Information section at the end of this article.

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