

# Black and Minority Ethnic Groups' Perception and Experience of Early Intervention in Psychosis Services in the United Kingdom

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## Abstract

In the United Kingdom, Black and minority ethnic (BME) service users experience adverse pathways into mental health care. Ethnic differences are evident even at first-episode psychosis; therefore, contributory factors must operate prior to first presentation to psychiatric services. This study examines the cultural appropriateness, accessibility, and acceptability of the Early Intervention (EI) for Psychosis Services in Birmingham (the United Kingdom) in improving the experience of care and outcomes for BME patients. Thirteen focus groups were conducted with EI service users ( $n = 22$ ), carers ( $n = 11$ ), community and voluntary sector organizations ( $n = 6$ ), service commissioners ( $n = 10$ ), EI professionals ( $n = 9$ ), and spiritual care representatives ( $n = 8$ ). Data were analyzed using a thematic approach and framework analysis. Findings suggest that service users and carers have multiple, competing, and contrasting explanatory models of illness. For many BME service users, help-seeking involves support from faith/spiritual healers, before seeking medical intervention. EI clinicians perceive that help-seeking from faith institutions in Asian service users might lead to treatment delays. The value of proactively including service user's religious and spiritual perspectives and experiences in the initial assessment and therapy is recognized. However, clinicians acknowledge that they have limited spiritual/religious or cultural awareness training. There is little collaborative working between mental health services and voluntary and community organizations to meet cultural, spiritual, and individual needs. Mental health services need to develop innovative collaborative models to deliver holistic and person-centered care.

## Keywords

Black and minority ethnic (BME) service users, carers, culture, beliefs, early intervention (EI) services

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In the past 20 years, the United Kingdom has become more ethnically diverse as the number and proportion of people from Black and minority ethnic (BME) communities has increased. Birmingham is the second largest city in the United Kingdom with a socioeconomically and culturally diverse population. British Pakistani (13.5%) is the largest minority group, followed by Indian (6.0%) and Black Caribbean (4.4%; Birmingham City Council, n.d.). For over two decades, there has also been a significant concern about the relationship between BME groups, especially among young Afro-Caribbean men and mental health services in the United Kingdom (Sainsbury Centre for Mental Health, 2002). BME groups have disproportionately high rates of psychosis and experience more adverse pathways into care (Morgan, Mallett, Hutchinson, & Leff, 2004; Singh, Greenwood, White, & Churchill, 2007). It has also been argued that knowledge and training required to offer culturally sensitive interventions to BME service users are either unavailable or poorly evidenced (Penny, Newton, & Larkin, 2009).

## **BME Explanatory Models of Health and Illness**

Anthropological perspectives of health and illness suggest that a decision to seek care is, in part, mediated by beliefs about illness causality as well as the wider social and cultural networks (Helman, 2007; Kleinman, 1978). "Cultural interpretations of mental illness held by members of a society or social group strongly influence their response to persons who are ill and both directly and indirectly influence the course of the illness" (Good, 1997, p. 234) and help-seeking behavior. Explanatory models represent personal concepts utilized to describe the causes and course of their mental illness (Sewell, 2011). Recent debates highlighted that some people can move from one strongly held view to another relatively quickly and unproblematically, forming an exploratory map rather than an explanatory model (Williams & Healy, 2001). Such beliefs should be regarded as "a map of possibilities, which provides a framework for the ongoing process of making sense and seeking meaning" (Williams & Healy, 2001, p. 473).

In studies examining understanding and experience of mental health services for BME populations in the United Kingdom, the most frequently mentioned causes of mental health illness were social stress, family problems, and the will of God (Hatfield, Mohamad, Rahim, & Tanweer, 1996; Rabiee & Smith, 2013), as well as the result of "bad thoughts," lack of will power, and weakness in personality (Suan & Tyler, 1990).

In Islamic faith,

Jinns are a race of created beings that are made of smokeless fire, they live with human beings and share their activities, and though they see us they cannot be seen. Jinns are believed to come in two forms: believers and non-believers that can possess a human being. (Rashid, Copello, & Birchwood, 2011, p. 7)

Studies of psychiatric patients have found that belief in supernatural causes, such as possession by jinns, has led to help-seeking from traditional or religious faith healers such as Imams (Muslim religious leaders) before seeking psychiatric help, demonstrating the influence of community-held cultural beliefs of society in help-seeking (Leavey, Loewenthal, & King, 2007).

Stigma and shame have been heavily implicated in poor help-seeking behavior (Corrigan, Edwards, Green, Lickey, & Penn, 2001), and profoundly stigmatizing community attitudes about mental illness can determine religious rather than a psychiatric help-seeking for such cases (Leavey et al., 2007). Lack of education and information has also been considered to be an attributing factor in such explanations of mental illness in the United Kingdom (Dein & Napier, 2008) and in developing countries (Srinivasan & Thara, 2001). However, other research suggests that supernatural causes of schizophrenia are strongly held by BME groups, in particular those from the Indian subcontinent, despite knowledge of mental illness (see Banerjee & Roy, 1998; Das et al., 2006).

## Early Intervention (EI) Services in the United Kingdom

EI services provide a multidisciplinary, outreach service for young people aged between 14 and 35 years old experiencing a first episode of psychosis. They are designed to improve access and provide effective and evidence-based care in low-stigma, community settings (Tait, Birchwood, & Trower, 2003) with the aim of reducing the duration of untreated psychosis and providing a sustained treatment through improved service engagement at the onset of psychosis. EI services are now part of mainstream psychiatric care in England. However, it is unclear whether generic EI services meet the specific demands and challenges of providing care for BME patients. To engage with BME service users and their families successfully, EI teams need to understand their needs and expectations, and in particular, the cultural appropriateness, accessibility, and acceptability of EI services (Department of Health, 2005).

This article is part of the ENRICH research program on Ethnicity, detention and early intervention: reducing inequalities and improving outcomes for black and minority ethnic patients, which aimed to understand and explore pathways, outcomes, and experiences of care in BME groups in Birmingham. The objectives were to understand challenges facing mental health service provision in relation to cultural appropriateness, accessibility, and acceptability by BME groups and develop ways forward in providing cross-cultural mental health care to reduce ethnic disparities in care and outcome. In this article, we report views expressed by service users and carers on their mental health needs and their experience of EI services. The perceived needs and preferences of BME groups as expressed by providers of local services, including voluntary and community organization representatives, EI service professionals, and spiritual care team representatives, as well as commissioners of local services are also discussed. The conceptual framework utilized is based on attempting to understand the comprehensive views, perspectives, and experiences of various stakeholders to identify the answers to the questions: "How easily reached and suitable are Early Intervention Services for the ethnic and cultural needs of BME communities in Birmingham?" and "How can these be improved?"

## Method

### *Design*

This study based its epistemology within the interpretative paradigm (Flick, 2006), aiming to explore the experience and understanding of service users, carers, and EI services (Penny et al., 2009). A qualitative method was chosen as it has the potential to provide rich data that reveal beliefs, needs, and preferences in health care (Burr, 2002). Using a topic guide, focus group interviews were conducted with service users, carers, health professionals, and key stakeholders from voluntary sector and community groups, commissioners and representatives of spiritual care. Each of these groups were purposely included to uncover any differences and discrepancies or similarities that exist between professionals delivering EI services and those receiving these services. Discussions with each of these groups were, therefore, held to highlight any existing examples of best practice or areas of improvement needed to ensure that EI services are culturally appropriate, accessible, and acceptable for BME service users and their carers. A topic guide was developed following an extended literature review and after discussion with the project steering group. The steering group consisted of academics and clinicians, a service user, a carer, a voluntary and community organization representative, and members of the research team. The topic guide focused around the key questions: "How easily reached and suitable are Early Intervention Services for the ethnic and cultural needs of BME communities in Birmingham?" and "How can these be improved?"

Cultural appropriateness, accessibility, and acceptability of EI services were investigated within several domains, including asking participants the following: how they or the person they

care for first came into contact with EI services, where they sought help before being referred to EI services, the impact of cultural/religious/spiritual beliefs on alternative help-seeking, their understanding and experience of the EI services, their experience and/or knowledge of the assessment process and perceived respect for cultural needs, availability of interpreters and information leaflets in appropriate languages and levels of understanding, whether they had any choices in terms of the gender or ethnicity of the professionals they saw, ethnic mix of the treatment teams, services, and local provision of culturally appropriate “talking therapies.” Questions were initially piloted with two Early Intervention Service (EIS) service users to ensure that they were suitable prior to study commencement. Demographic data were also collected for service user and carer participants but not for other groups, to uncover whether any differences in experiences existed in terms of ethnicity, gender, or age. It should be noted that only the gender details of providers were collated, apart from commissioners, for which no demographic details were collated. Other demographic details of providers were not collated due to issues around anonymity. The location of the EI team and other provider organizations included in the study meant that providing such individual characteristics may have made participants identifiable.

### Participants

The study was carried out in and with the support of Birmingham and Solihull Mental Health Foundation Trust. All participants in this study were recruited from EIS Birmingham.

**Service users.** The aim was to recruit participants who represent the BME ethnic mix within each locality in the city. Hence, the inclusion criteria for service users were to be from a BME background and a current or past EIS user.

Researchers spoke to service managers and clinicians directly to identify any potential participants. The relevant clinician asked potential participant(s) if they would be happy to be contacted by the research team. If they agreed, one of the research teams telephoned the potential participant to briefly inform them about the study. All potential participants were sent an invitation letter and an information sheet. This was followed by a telephone call from the research team to confirm whether they were willing to participate in the study.

A total of 80 potential participants were identified of whom 24 participants (30%; including two service users who participated in the pilot focus group) were recruited into the study; there were an equal number of males and females. The main reasons for lack of participation were either they were ill, that is, relapsed during the data collection phase (30%), not from a BME group (30%), or refused participation (10%). The majority described themselves as British Pakistani ( $n = 9$ ), followed by Black British-Caribbean ( $n = 5$ ), reflecting the ethnic profile of Birmingham population. The mean age was 22. Table 1 provides detailed information about the sociodemographic characteristics of the participants.

**Carers.** A total of 45 potential carer participants were identified from a range of sources, including voluntary/community organizations, service users who had participated in the service user focus groups, and one care coordinator from the EIS. Initially agreement of service users was sought before carers were approached. Once carers agreed to participate, the same procedure as recruiting service users was used. In total, 14 carers were recruited (31% of the potential sample), 3 of whom formed the pilot study focus group. This included 8 females and 3 males. The majority described themselves as Black British-Caribbean ( $n = 5$ ) and British Pakistani ( $n = 3$ ). The mean age was 42 (see Table 1).

**Voluntary and community organization representative.** An initial mapping exercise was conducted to identify voluntary and community organizations that served BME mental health service users

**Table 1.** Characteristics of Participants in the Six Service User Focus Groups and Three Carer Focus Groups.

	Gender		Age groups						Ethnicity						Religion/faith				
	F	M	18-25	26-35	36-45	46-55	56-65	66-75+	Asian/British	Asian/Bengali	Asian/British-Bengali	Asian/Black African <sup>a</sup>	Asian/Black British	Asian/Black Caribbean <sup>b</sup>	Asian/Black/Other <sup>c</sup>	Black/Muslim	Black/Christian <sup>d</sup>	Black/None <sup>e</sup>	Black/Other <sup>f</sup>
Service users	11	11	14	8	3	4	3	1	9	1	3	3	8	1	11	5	3	3	3
Carers	8	3	3	4	3	4	3	1	3	3	2	5	5	1	3	8	3	3	3

Note. Pilot service user and carer focus groups are not included.

<sup>a</sup>Includes one mixed White and Black African (carer).

<sup>b</sup>Includes four mixed White and Black Caribbean (three service users and one carer).

<sup>c</sup>Includes one Arab (user) one White British (carer).

<sup>d</sup>Includes two Catholic (carers).

<sup>e</sup>Includes one unknown (service user).

<sup>f</sup>Includes one "Belief in one God" and two "other" (service user).

and their carers across Birmingham. Having accessed a number of sources, 40 of 138 existing organizations were eventually identified as serving BME mental health service users and their carers. All 40 were contacted, and 6 agreed to participate. This included four females and two males. The main reason for the lack of participation was other work commitments (approximately 80%).

*Commissioners.* The U.K. health and social care organization is divided into two groups: those who provide and those who commission the services. All 10 commissioners contacted agreed to participate.

*Professionals.* An email was circulated to all EIS staff members ( $n = 90$ ) and the first author visited each individual team base to discuss the study. Nine interested clinicians, consisting of five females and four males, were finally recruited. This included service managers ( $n = 2$ ), care coordinator ( $n = 1$ ), senior social worker ( $n = 1$ ), community psychiatric nurses ( $n = 2$ ), student nurse ( $n = 1$ ), vocational worker ( $n = 1$ ), and senior occupational therapist ( $n = 1$ ). The main reason for other professionals' refusal was cited as other work commitments on the date of the focus group (approximately 90%).

*Spiritual care representatives.* In liaison with the head of spiritual care in Birmingham and Solihull Mental Health Foundation Trust, a total of 11 spiritual care representatives were contacted, and 8 were recruited (73%), consisting of 3 females and 5 males. This included the service manager and chaplains, and volunteers from a multitude of diverse faith backgrounds, including Christian chaplains, Muslim Imams, and a humanist.

### *Ethical Approval and Informed Consent*

Ethical approval was granted by the Warwickshire Research Ethics Committee; the study was also approved by the Birmingham and Solihull Mental Health Foundation Trust research and development unit prior to approaching any potential participants. All participants gave their informed consent before the start of the focus group interview.

### *Data Collection and Analysis*

All focus groups were facilitated by the first author to ensure consistency of approach, and accompanied by a note-taker, who observed and recorded the non-verbal interactions and documented the general content of the discussion to aid later analysis of the data. De-briefing meetings were held immediately after each focus group between the facilitator and the note-taker where thoughts and perceptions about the content of discussions were recorded. Prior to conducting focus group interviews, a pilot focus group with service users and one with carers were conducted to test the topic guide and assess the feasibility of focus group and time required for carrying out the main focus group(s).

Overall a total number of 13 focus groups with 66 participants were convened. This included 6 focus groups with service users ( $n = 22$ ): 3 focus groups with carers ( $n = 11$ ), 1 with voluntary and community organization representatives ( $n = 11$ ), 1 with commissioners ( $n = 10$ ), 1 with EIS professionals ( $n = 9$ ), and 1 with spiritual care representatives ( $n = 8$ ). All focus groups with service users were conducted in English apart from one in which an interpreter was used to translate for one service user in Arabic, in the same focus group the facilitator translated for another service user in Urdu. All focus groups with carers were conducted in English apart from two in which the facilitator translated on behalf of three carers in Urdu. All other stakeholder focus groups were conducted in English. Each focus group lasted up to 90 min.

**Table 2.** Breakdown of Themes and Sub-Themes.

Themes	Sub-themes
1. Help-seeking	Crisis Barriers to help-seeking Mistrust of services
2. Culture and beliefs	Ambiguity and uncertainty Knowledge and uncertainty
3. Social stigma and shame	
4. Experience of EI service	User choice Interpreters Continuity and discontinuity of care Treatment, support, and recovery Withholding information
5. Improving BME access and experience of services	Education and raise awareness Meeting cultural, spiritual, religious, and individual needs Cultural appropriateness Collaborative working with voluntary and community organizations

Each interview was audio taped and transcribed verbatim. Analysis was conducted using a thematic approach (Ritchie & Spencer, 2002) to systematically code, classify, and organize the focus group content into key themes and sub-themes. Based on a thematic approach and also drawing on Krueger and Casey's (2009) framework analysis, initially, each line of the transcript was numbered and then printed and read by the facilitator and another member of the research team to identify recurring concepts and categories. These transcripts were then reread by the facilitator to identify how these concepts and categories formed the basis of a conceptual thematic framework (Ritchie & Spencer, 2002). This framework was used to code and classify data and then modified and refined throughout the analysis to reflect the content and issues expressed by respondents across all focus groups. These coded categories were then sorted into broader core themes based on similarity and content by the facilitator and checked by the second author. Illustrative quotes are provided to aid transparency of categorization and theme representation. To protect anonymity, every participant in each focus group was given a letter code and assigned a number: that is, service users (SU), carers (C), professionals (P), voluntary and community organizations (V), commissioners (COM), and spiritual care representatives (SC).

## Results and Discussion

Five key cross-cutting and overlapping themes emerged as crucial in determining the accessibility, acceptability, and appropriateness of EI services in meeting the ethnic and cultural needs of BME communities across all stakeholder focus groups. These five themes (see Table 2) were as follows: (a) help-seeking, (b) culture and beliefs, (c) social stigma and shame, (d) experience of EIS, and (e) improving BME access and experience of services. To provide a cohesive result of the data collected and discussions based on the thematic framework approach (Ritchie & Spencer, 2002), the views of various stakeholders are collated and presented under each theme in the following sections, as opposed to being presented separately.

### *Theme: 1 Help-Seeking*

**Crisis.** The majority of service users reached mental health services through a "crisis." Even in cases where carers recognized the need for medical help, help was not sought until service users

reached a “crisis” point, where the patient was perceived either as dangerous to himself or herself or to others. In some cases, carers obtained appropriate medical support by exaggerating service user’s symptoms: “I got the police involved, we called the police, something’s wrong, I had to tell lies . . . he’s going to do something because he’s talking about the Taliban . . .” (C1, British Pakistani, female).

**Barriers to help-seeking.** 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 across age, gender, and ethnicity: “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). Carers and voluntary and community organization representatives believed that GPs needed further training in detecting the symptoms of mental illness and realize that carers were best placed to detect any changes in behavior (symptoms) of the service user.

Service users who were unable to obtain appropriate support were often left reliant on family and friends. This was not necessarily deemed beneficial when those called upon for support lacked knowledge and understanding of mental illness and the appropriate services available for treatment:

. . . if your family and friends around you don’t know what to do and you’re relying on them, to try and support you, it’s really difficult, because, I mean they didn’t know what to do . . . if they . . . haven’t got any professional help for it, you’re stuck . . . (V15, female)

**Mistrust of services.** Some commissioners, EIS professionals, and voluntary community organization representatives felt that BME communities, particularly those from Black African/Caribbean backgrounds, mistrusted services, and this contributed to delay in help-seeking:

I think they . . . some of the African Caribbean community . . . [take] a very rational view that Mental Health Services are punitive, they’re sectioning a lot of them . . . isn’t that the cycle where therefore people don’t come forward until they’re at their most critical and key stages. Therefore when they do come forward it’s likely to be the Police bringing them in, . . . half of the admissions for African Caribbean male is by the Police, . . . it just goes to prove that’s what Mental Health systems do for you. And if you’re an African Caribbean man you don’t go anywhere near them . . . so it’s breaking that. (COM4)

## Theme 2: Culture and Beliefs

All service users and their carers held multiple explanatory models and “exploratory maps” (Williams & Healy, 2001) of illness, which were often competing and contrasting as well as interchangeable. Some carers cited religious and cultural beliefs as explanations for initial symptoms of mental illness such as supernatural forces or black magic: “. . . this went on for a period of time where it was getting worse for him . . . I started to think, as a black person there was something wrong, I thought there’s a ghost in the place” (C12, Black British-Caribbean, female). The fear of being unwell played an important role in consolidating beliefs in religious and cultural explanations of illness, particularly for service users from Pakistani backgrounds. Religion gave them a sense of structure and purpose and a framework within which to understand emerging symptoms: “. . . I’m actually a grateful person and a very lucky person because to go through what I went through it goes to show that I’m in God’s memory, God hasn’t forgotten me you know” (SU20, British Pakistani, male).

For majority of service users, family and community members encouraged faith-based help-seeking. This included visiting multiple faith and spiritual healers. For most, this practice proved



to be beneficial and positive in bringing solace. Some service users from Pakistani Muslim backgrounds also continued to visit faith healers after coming to EIS. A minority became victims of financial exploitation:

. . . he asked me for £500 . . . I actually went to the cash point withdrew £500, . . . he gave me that egg anyway and he goes when you gonna go somewhere far, throw it over your shoulder and pray for what you want and don't look back and walk away and don't go back there again . . . (SU13, British Pakistani, female)

### *Ambiguity and Uncertainty*

There was ambiguity and uncertainty both in relation to explanations of symptoms and cultural understandings of mental illness, especially among second-generation South Asian service users who felt that their parents and community members believed in black magic but the users themselves were unsure: "I still don't quite understand why I got ill . . . they say my sister-in-law . . . is evil . . . They say that but how can she be like that?" (SU22, British Pakistani, male).

Cultural beliefs often competed and contrasted with medical explanations: "My mother believes that cure will come from God, that God will come through and I believe that as well, obviously medicine is here for a reason as well so . . ." (SU15, British Pakistani, female). Even where service users and carers recognized that substance and alcohol abuse were potential causes of developing psychosis, these beliefs were interchangeable with cultural/religious belief systems: ". . . 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).

*Knowledge and understanding.* Lack of knowledge and understanding was perceived to be a key barrier to delay appropriate help-seeking by commissioners, voluntary and community organization representatives: ". . . it's not that they don't, don't want to access the service, it's just they don't even know about the services. They're not aware of it for one" (V18, female). This was reiterated by some carers who stated that they did not discuss the issue of mental illness with their faith community due to fear of facing negative reactions as a result of lack of knowledge and understanding: "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).

### *Theme 3: Social Stigma and Shame*

The fear of social stigma and shame delayed help-seeking in all focus groups, particularly in the South Asian communities: "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). Voluntary and community organization representatives and spiritual care representatives emphasized that the label of mental illness held repercussions for carers and family members affecting marriage prospects and positions within South Asian communities: "Sometimes people think mental health is kind of a disease that will catch people" (V16, female).

A few spiritual care representatives reiterated this point by giving examples of facing social stigma by working with mental health service users:

. . . unfortunately, stigma is not only with them [it is] with us as well, one of my friends . . . he said, "If you work in a Mental Hospital, you must have been affected by it, and I don't like to be affected by you." (SC6, male)

Equally, a voluntary and community organization representative stated that the stigma about mental illness was a factor for BME communities not attending local mental-health-awareness-related events:

I find that there's a really big issue with engaging with, [or] in Workshops, . . . there's an issue, cause as soon as you advertise a Workshop, and say, you know, you have to almost hide the fact you're . . . gonna be talking about mental health. (V15, female)

It was thought that people who needed the support of services were failing to reach services until crisis.

In addition to negative attitudes toward mental illness particularly among South Asian communities, there was failure to recognize the impact of mental illness on an individual's life and functioning. As one service user stated, "[They don't understand] the actual problems that people get and how horrible it can be . . . They don't know how to identify it as well" (SU7, British Pakistani, female).

#### *Theme 4: Experience of EIS*

Although the majority of service users accessed mental health care after a crisis (Singh et al., 2013), once they were in receipt of the service, EI professionals were generally viewed as appropriate, accommodating, respectful, and understanding in terms of service users' needs: ". . . no flaw, no disappointment, even in the night when we call, they were always there" (C1, British Pakistani, female).

Once in receipt of the service, there were several factors that affected the overall experience of EIS by service users and their carers as detailed in the following sub-sections:

**User choice.** 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, 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.

**Interpreters.** All service users were unanimous that EIS considered language needs and provided interpreters when needed. However, a major concern expressed by professionals, and voluntary and community organization representatives was the availability of appropriate interpreters. Professionals stressed that the quality, reliability, and competence of interpreters were questionable:

I'm not sure what level or degree of training these people have in mental health . . . the service user was very angry and conveyed that he really wanted to belt this guy because he was so objectionable, to what the client was expressing, which really undoes a lot of the work that we do with engagement. (P2, male)

Examples were given about interpreters behaving inappropriately, and concerns were raised that interpreters might breach confidentiality if they were from the same close-knit BME community: "You don't always take it on board that people know of people, who know people" (P3, female).

**Continuity/discontinuity of care.** One of the key negative aspects of care was the high staff turnover. Service users and carers formed strong relationships with EIS staff (particularly care coordinators) and became anxious when there were staff changes: ". . . my son is already worrying. It's

worrying because he's saying when [care coordinator] gone, because to him [care coordinator is] everything right now" (C12, Black British-Caribbean, female).

High turnover of staff meant that service users had to repeat the details of events. Repeating the details of the negative events that occurred leading up to developing mental illness to different professionals was often described as "traumatic" and considered to have a detrimental effect on their well-being: "For me it was a negative thing because I wasn't confident enough to disclose to someone who is new so I had to withdraw a bit" (SU5, Black British-African, female). This also echoes Rabiee and Smith's (2014) findings from a study exploring Black African and African Caribbean mental health service users' experiences in Birmingham.

*Treatment, support, and recovery.* All carers were positive about the treatment provided by EIS, particularly in terms of the positive effect of medication. However, the majority of service users wanted a "cure": ". . . 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).

Professionals acknowledged that the Internet had made information accessible, and service users were knowledgeable about treatment options, as well as the ingredients within certain medications. This meant that service users whose religious practice and beliefs forbade the consumption of pork or pork products refused to take medication, which contained such ingredients. Professionals acknowledged this but also stated that they were unaware of the alternative treatments/medication available.

The majority of service users were offered alternative therapies (i.e., relaxation therapy) or talking therapies (i.e., counseling/psychotherapy), but a few service users did not see their potential benefits, because they could not see the "immediate benefits." Some service users wanted emotional support and an example was given of counselors referring South Asian service users back to a voluntary sector organization to receive such "emotional support."

Some voluntary and community representatives stated that efforts needed to be made to educate service users about the long-term benefits of such treatment and the approach taken by therapists needed to consider cultural and individual needs. Examples of what were deemed as "culturally appropriate" talking therapies were given. This included the importance of having a "qualified Chinese speaking counselor . . . [who speaks] the same dialect" (V18, female), to combat language barriers; the "Lateef project" a Muslim telephone counseling service. However, this service was not deemed as appropriate for all service users as it did not consider individual needs: "But I have a client who go into anxiety, . . . she don't pick the phone at home, once the phone rings, she gets panic . . . and she always have that kind of fear, 'somebody's listening my conversation'" (V16, female).

The majority of voluntary and community organization representatives stressed that services geared toward BME service users needed to consider the individual needs of the service user not just assumed preferences based on their religious or cultural identities, hence adopting a holistic and "person-centered" approach (Bergeson & Dean, 2006).

*Withholding information.* In general, where South Asian service users were continuing to seek support from traditional healers (i.e., faith/spiritual), they did not disclose this to EIS professionals. They believed that professionals (i.e., care coordinators and doctors) would not understand their views/perceptions of health and well-being, or the use of traditional remedies for the treatment of distress or illness including psychological and emotional difficulties within a spiritual framework: "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).

Similarly, spiritual care representatives stated that they only received "occasional referrals" from EIS and service users were reluctant to disclose their faith and the religious practices and beliefs associated due to the fear that this would be misconstrued by professionals as being part of their mental illness.

### Theme 5: Improving BME Access and Experience of Services

When exploring this main theme, the following four sub-themes emerged:

#### *Educate and raise awareness*

Maybe educating Asian people again about mental health problems because a lot of them don't understand it, even like the young generation people. I've got some Asian friends and they don't really understand it so I never bothered telling them. (SU7, British Pakistani, female)

There was a consensus among voluntary and community organization representatives that due to lack of knowledge and understanding of medical explanations, BME service users were most likely to seek spiritual/religious and/or cultural explanations of symptoms in the first instance. As a result, the majority of voluntary and community and a minority of spiritual care representatives suggested that "faith healers" such as Imams needed to develop knowledge about mental illness and the services available. The general consensus was that professionals needed to work closely with faith healers to provide culturally competent care.

*Meeting cultural, spiritual, religious, and individual needs.* Concerns were also raised about professionals' lack of knowledge and understanding of cultural and spiritual needs of their clients:

We had . . . a Baptismal Service, and, quite a number of the staff came, and one of the service users suddenly spoke in tongues, . . . The result of that was a bit of a shock wave, and his psychiatrist was thinking of upping his medication . . . So of course I was then, able to speak to that particular consultant psychiatrist . . . I acquainted him to the fact that according to, the Christian Scriptures, this was something that was happening in the early Christian days, with all the early Christian leaders in the beginning, and from time to time it happens. So this chap said, this psychiatrist said, "Oh, so I don't need to up his medication?" I said, "No, . . . this happens." (SC3, male)

This was echoed by other participants:

Well, I think this is where it's important that the health care professionals and the psychiatrists or consultants and the nurses, work with the Imams and try and understand Islamic perspective on mental health . . . these are the things that one needs to look at, . . . which would differentiate from, someone, suddenly going into this transit of speaking in tongues [or becoming mentally unwell]. (SC1, male)

*Cultural appropriateness.* The majority of professionals recognized that a great variation exists between and within cultures, and diverse views held by service users in terms of explanations of mental illness and preferred treatment options differ; hence, these issues needed to be considered on an individual basis in care plans. Professionals also recognized that although some information around individuals' beliefs and values was collated through the "Health and Social Care assessment," "this was underutilized" (P5, male and P6, female), the main reason being workload and time constraints: ". . . in, my experience I think we're a bit behind in terms of understanding the depth of other cultures, sort of different ways of looking at things and so I think it's tolerated more than embraced" (P6, female).

There seemed to be a general consensus that there was not enough cultural training given to EIS staff. Instead, EIS staff learnt about nuances between different cultural groups through speaking to colleagues from the same background as the service users as well as by making mistakes and learning through experience: ". . . I've never had a day of dedicated cultural awareness [other than the one day Trust cultural and diversity training] . . . so I've learned through blunders I've made. Through asking families, from colleagues" (P6, female).

*Collaborative working with voluntary and community organizations.* Commissioners considered voluntary and community organizations to be “key partners” in terms of engaging with communities. They suggested that trust could be established by promoting services within local communities. Community development workers were also highlighted as playing a key role in overcoming trust issues and bridging the gap between the local BME communities and services by raising awareness of mental health issues and the services available.

However, professionals were not liaising with community development workers and had little knowledge of the voluntary or community sector organizations available locally. Equally, of the six voluntary and community service representatives participating in the focus groups, only two representatives had an understanding of the EIS. EIS professionals also lacked the capacity and time to liaise with voluntary and community organizations. Instead, they stated an “up to date” directory with details of such services needed to be made available.

## Conclusion

This large qualitative study sets out to explore user, carer, and provider perspectives on the appropriateness, accessibility, and acceptability of EI services for BME groups. We found these to be complex and challenging factors that include the following:

### *Understanding Mental Illness and Help-Seeking*

We found that users and carers have multiple explanatory models of illness, and these were also competing and contrasting (Dein & Sembhi, 2001; Williams & Healy, 2001), both in relation to explanations of symptoms and cultural understandings of mental illness. We found some narrative data that these explanatory models influence initial help-seeking behavior. For instance, some individuals from Pakistani Muslim backgrounds sought support from faith healers before seeking medical support. Often, this support was initiated by family and friends. Social stigma and shame (Corrigan et al., 2001), coupled with mistrust of services and lack of understanding and knowledge (Dein & Napier, 2008), of the symptoms and causes of mental illness are equally, if not more, influential in delaying initial appropriate help-seeking and acceptance of mental illness.

Primary care understanding and referral to EI services were seen as a barrier to appropriate medical support. Previous studies show that a majority of GPs have no postgraduate mental health training and that they often have negative opinions about providing care for people with schizophrenia (Lawrie et al., 1998). Other research has shown that GPs believe that they contribute little to the care of people with serious mental illness in general, and that the incidence of first-episode psychosis is too low to warrant more active involvement (Bindman et al., 1997). As suggested by Lester, Birchwood, Freemantle, Michail, and Tait (2009), we also found that training GPs about the EI services may facilitate access to such specialist teams for early psychosis.

### *Appropriate Treatment*

Many BME users equated recovery with cure, a return to how things were before the illness occurred. The concept of recovery has a multitude of meanings and is being increasingly debated within mental health discourse (Care Services Improvement Partnership, Royal College of Psychiatrists & Social Care Institute for Excellence, 2007). Our findings suggest that BME users and carers need a clearer explanation about the course and outcome of psychotic disorders with better understanding of recovery, management of illness, and realistic outcomes. This is not dissimilar to the way in which health professionals promote self-management for chronic conditions, that is, diabetes (Minet, Lønvig, Henriksen, & Wagner, 2011).

## *Interpreters*

Our results suggest that the quality, reliability, and competence of interpreters currently being used are questionable. Interpreters are recruited via established links with interpreting services within the National Health Service (NHS). However, it should be noted that the United Kingdom has never had a coherent policy on standards of interpreting in health care or any other part of the public sector. Also the training and practice standards for professional interpreters are not statutory (Cambridge, Singh, & Johnson, 2012). As Cambridge et al. (2012) highlight, “interpreting, translation and language support . . . must be delivered to a highly trained professional standard”; however, this remains a neglected area of provision in the United Kingdom (p. 121). Clearly, training needs to be put in place, which gives interpreters the knowledge to translate medical jargon appropriately, and emphasizes that their role is translation only and confidentiality of all should also be respected.

## *Competent Health Professionals*

Our findings argue against creating ethnic-specific services, as has been recommended in the past. All our stakeholders argued against BME/ethnic-specific EIS. BME users and carers repeatedly asked for competent and compassionate care and to be treated as individuals rather than group members, regardless of the gender or ethnicity of the clinician or the service provider (Rabiee & Smith, 2013). An assessment of a user’s religious or spiritual beliefs, and respecting their beliefs and experiences need to unfold progressively within the context of a secure therapeutic relationship (Coyle & Lochner, 2011).

Other studies that have specifically explored the role of institutional racism in mental health care have also found that BME users and carers predominantly want good care from skilled, experienced, and culturally informed clinicians and services (Weich et al., 2012). BME service users are not asking for BME-specific measures; they want to be able to share their spiritual/religious and cultural beliefs with mental health service professionals. The fear of negative reactions and/or lack of understanding appear to prevent service users disclosing to EIS professionals that they are seeking support from faith or spiritual healers. Such fears are not unfounded as EIS professionals receive limited spiritual/religious and cultural awareness training with regard to ethnic communities. Equally, they receive limited training in how their own beliefs affect their professional practice, an issue that is in much need of further debate and consideration (Pelechova, Wiscarson, & Tracy, 2012).

Our findings echo previous studies that in addition to cultural competency, “spiritual competency” is required for the provision of appropriate and individualized patient care in general and in psychiatry in particular (Durà-Vilà, Hagger, Dein, & Leavey, 2011; Rabiee & Smith, 2014).

## *Limitations*

One of the limitations of this study is low response rate, despite attempts to increase the pool of respondents. The low response rate introduces sampling bias. The lowest response rate in our study was from voluntary and community sector organization representatives and mental health professionals due to their workload and unforeseen circumstances. The service users and carer participants are mainly from Pakistani and African Caribbean backgrounds, representing the two largest BME ethnic backgrounds in the city. Although other BME groups’ views are presented, our findings must be interpreted with caution when applied to ethnic groups not included in this study. Apart from service users and carers, we did not collate individual characteristics of any other focus group participants. In hindsight, it may have been useful to have details of individual characteristics such as age and ethnicity for all participants, allowing for further comparisons to

be made. Furthermore, we did not distinguish between ethnicity and culture; for instance, an attribution such as belief in *jinn*s is a cultural and religious phenomenon rather than a phenomenon of ethnicity. Nonetheless, the findings highlight a number of new issues and implications for the accessibility, acceptability, and appropriateness of U.K. EI services for all BME groups, which need to be addressed. In addition, broader issues raised in relation to the needs for cultural and spiritual competency of health professionals, interpreting services, and respecting individual's health and spiritual beliefs have relevance for wider community groups and other health and social care settings.

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