

# **An investigation of Black Minority Ethnic service users' perception of their needs within a North London Mental Health NHS Trust: A Phenomenological Qualitative Study**

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*This study was conducted to find out from service users from a black and minority ethnic background (BME) how they perceive their needs were being met when being cared for in a Mental Health Trust. The participants were drawn from the black ethnic group including Black African, Black Caribbean, Black British and Black Mixed Race.*

*The study was a descriptive phenomenological study whereby the participants were interviewed using a semi structured interview via the use of a topic guide. The study was informed by the mental health trust' priorities under the Race Equality Scheme to meet the needs of the diverse group which it serves.*

*The interviews were tape recorded and the data collated was transcribed verbatim. Six themes and subsequent sub-themes were identified following thematic analysis of the data. The findings from this research study suggest that BME service users did not express any negative*

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*views about the care they received by the mental health trust. Some of the BME participants however stated that they had to wait varying lengths on time before they received specialist psychological services. The participants expressed that they experienced stigma and discrimination by the police, criminal justice system, employment and the wider public.*

*A number of recommendations were proposed including the development of a 5-day training programme to support the police and other social, welfare and charitable services in enhancing their knowledge and skill about mental illness. Mental health professionals to continue to challenge discrimination through social media campaigns, video and publications. There was also a recommendation made regarding the 6Cs - Care, Communication, Compassion, Courage, Competence and Commitment. In that the term 'Consistency' should be added to make a 7th C. Other Implications for best practice were also noted.*

**Key Words:** BME service users, needs, mental illness, support, service user experience.

## **Introduction**

A comprehensive plan for eliminating discrimination and achieving equality in mental health care for all people of Black and Minority Ethnic status (BME) was put forward by Department of Health, (Department of Health, 2005a). The publication of this document was a significant change in supporting the work within Mental Health Trusts when considering the needs of service users (SU) from a BME background. This was fully supported by the Equality Act (2010) which made it a legal requirement under the Act, that NHS Trusts publish an annual report on their performance in the delivery of fair and equitable services, promoting equal opportunities and fostering good relationships between the different groups of SUs and NHS Mental Health Nursing staff.

A review commissioned by the former Prime Minister Teresa May in 2017 was conducted in 2018. The report noted with concern the disproportionate number of people from black and minority ethnicities detained under the Mental Health Act 1983 (Department of Health, 1983). Whilst experiences vary across different ethnic minority groups, the report highlighted

that the reviewers were “*particularly concerned by the excessively poorer experiences and outcomes of individuals from black African and Caribbean communities,*” (Department of Health, 2018, p. 58). In seeking reasons why this is so the report emphasised that research has evidently aligned health inequalities to racism as well as socioeconomic factors (such as inequalities in housing, local neighbourhoods, education and employment), (Department of Health, 2018, p. 163). Similar evidence has been found by authors such as (CQC, 2020; 2018; Department of Health, 2018; Memon *et al.* 2016; Brui & Singh, 2004; Bhui & Bhugra, 2002a), that people from a BME background encounter difficulties in accessing and using mental health services.

Ethnicity or ethnic group has been defined as a group of people whose members identify with each other through a common heritage, often consisting of a common language, common culture (which can include a religion) and or an ideology which stresses a common ancestry, (Institute of Race Relations, 2019). Culture is a social construct which is characterised by the behaviour and attitudes of a social group (Fernando, 1991). In a similar vein, Radcliffe, (2004, p. 28), suggested that “*the precise nature of ethnicity is highly contested as the term tends to be used loosely to imply commonalities of language, religion, identity, national origin and or even skin colour*”.

Notwithstanding, Bhopal suggested that:

*ethnicity is a multi-faceted quality that refers to the group to which people belong, and/or are perceived to belong, as a result of certain shared characteristics, including geographical and ancestral origins, but particularly cultural traditions and languages (2003, p. 441).*

Ethnicity varies from race, nationality, religion, and migrant status, sometimes in subtle ways, but may include aspects of these other concepts (Bhopal, 2003). While race and ethnicity are different, they are overlapping concepts that are often used synonymously (Nittle, 2020; McKenzie & Crowcroft, 1994). Notwithstanding Bunglawala (2019) observed that there were different acronyms used to describe people from ethnic minority background. Whilst acronyms are very ‘*catchy*’ and ‘*convenient*’ they are not always well thought through, have

negative connotations or are hurtful to people (Bunglawala, 2019). Okolosie, *et al.* (2015) highlighted advantages and disadvantages on the use of the acronyms and pondered on the fact that if the acronyms are scrapped what would they be replaced with.

Millar *et al.* (2015) noted that the history of SU involvement in mental health bestrides at least five decades. In 1983, the Griffiths Report spoke about the difficulties in hearing the authentic voice of the ultimate consumer of psychiatric services and suggested that health care should be measured by how it is perceived by users. In 1985 patients' councils in psychiatric services and mental health advocacy projects began to develop in the United Kingdom (UK), adopting an approach which broadly aimed to change mental health services dialogue and discussion, (Millar *et al.* 2015; Peck & Barker, 1997, p. 269). In that same year, '*survivors speak out*' (British Mental Health SUs' group), was formed which took a more campaigning stance (Peck and Barker, 1997). This approach brought to light the personal stories of mental health SUs in a wider political context. To this end, it could be argued that the emphasis of user involvement in decisions about their care has arisen from a number of factors: the perceived remoteness and unresponsiveness of services to the needs and wishes of users, an increasing diverse and discerning public and the demands of various groups, (Sharma *et al.*, 2016).

User involvement defines the process whereby individuals become actively involved in their health care, rather than be passive recipients of such services, (Neech *et al.*, 2018). Notwithstanding, Gee, Mcgarty and Babfield (2016), identified systemic barriers to user and carer participation. However, the concept of working in partnership with SUs is well established in health policy. To this end, the NHS Constitution pledged to patients that NHS staff will "*work in partnership with you, your family, carers and representatives*", (Department of Health, 2015, section 7).

In a qualitative study conducted by Lwembe *et al.* (2016) they found that the use of co-production helped to overcome barriers to accessing mental health services. The study highlighted an alternative model that could lead to delivery of patient-centred services to improve access and patient experience within mental health services, particularly for BME

communities. Lwembe *et al.* (2016) also found in their UK study that stigma and fear of disclosure, were acting concurrently with an apparent suspicion of the service during the initial assessment session, to provide a substantial barrier to engagement.

Nonetheless, Wright, Williams and Wilkinson (1998) purported that needs in health care is generally defined as the capacity to benefit. If health needs are to be identified, then an effective intervention should be offered to meet these needs and improve health. Notwithstanding, Clarke *et al.* (2019) proposed that a health intervention is:

*a combination of activities or strategies designed to assess, improve, maintain, promote, or modify health among individuals or an entire population. Interventions can include educational or care programmes, policy changes, environmental improvements, or health promotion campaigns (Clarke et al., 2019, p.1).*

Indeed, Thompson (2014) concluded that health needs assessment is used to set the policy agenda, plan services and target resources effectively to result in maximum health benefit for both individuals and populations

Mental health needs include broad domains of health and social functioning, which are necessary to survive and prosper in the community. Needs can be assessed from different perspectives, including staff, patient or carer, and have been differentiated into unmet needs and met needs (Phelan *et al.* 1995). A consensus emerged across Europe and Australasia that mental healthcare should be provided on the basis of need, with an intended goal of improving subjective quality of life (Department of Health, 2011; Lasalvia *et al.*, 2000).

## **Background to the research**

This study was conducted to enquire from SUs from a BME background on their perception of what their needs were and their experience of whether those needs were being met when being cared for in the NLMHT (Flood, 2021). The Trust recognised that it served a multi-

cultural population and identified the following priorities under the Race Equality Scheme to meet the needs of this diverse group:

- Improving information about the mental health needs of a diverse population which the Trust serves.
- Improving quality and cultural capability of inpatient care.
- Forming a partnership with local agencies to develop stronger links with the community.
- Continuing to enhance the early intervention and prevention services and improving access to the range of services that people need.

Several authors, (Halvorsrud *et al.* 2018; Brui & Singh, 2004; Bhui and Bhugra, 2002b; Keating *et al.* 2002), have expressed concern that SUs from a BME background encounter barriers both in accessing and using mental health services. Therefore, the aim of this descriptive phenomenological study was to provide an in-depth description of the BME SUs perception of their needs when being cared for by the Community Mental Health Teams in the NLMHT (Flood, 2021).

Hence, it is hoped that the information drawn from the study will give further insights into the needs of this specific group and address ways in which those needs could be met. The research question derived from practice and the literature, underpinning the study was:

**Research Question:**

Do service users from a BME background perceive that their needs are being met within the Mental Health Trust?

## **Methodology**

This study used a qualitative methodology. It has been suggested that there is a closer fit between the practice of nursing and qualitative research than any other methodological approach (Gullick & West, 2012; Miller, 2010). That is because subjective human feelings and emotions are difficult (or impossible) to quantify, (Holloway and Galvin, 2016; Forster, 2001). Therefore, in this study, a descriptive phenomenological approach was chosen as it helped to discuss the lived experience of the service users from a BME background.

## **Method**

A search through databases such as MEDLINE, PsycINFO and CINAHL revealed that much has been written about SUs being treated less favourably when accessing and using mental health services. For the purposes of this study the acronym 'BME' was used to identify the participants who took part in the study. The author in this study enquired from the participants what they perceived their needs to be and how those needs were being met within the North London Mental Health Trust (NLMHT) (Flood, 2021). This was done via the use of semi structured interviews.

As suggested by Qu and Dumay (2011), the interview guide ensures that the same thematic approach is applied during the interview. Therefore, below are the themes that made up the interview schedule for the research study:

- Needs for individual Care Planning.
- Ethnicity and equality.
- Access to information.
- Meeting needs in a crisis.
- Needs for timely treatment and support with mental distress.
- Need for ordinary living and long-term support.
- Need for personal growth and development.

## **Ethical issues**

Prior to conducting this study, the proposal was sent to the North Central London Research Consortium (NoCLoR) (a Trust funded research advisory body) for peer review. Ethical clearance was obtained at the National Research Ethics Service (NRES) 12/LO/1377. Written consent was sought from senior managers of the inpatient and community services to gain access to the participants. Once permission was granted the Care Co-ordinators (CCs) were approached via Community Mental Health Team Managers to agree the suitability of the SUs due to their vulnerability. Each of the participants gave their consent on the basis of information and knowledge about the research.

Seale *et al.* (2004) stated that research subjects have the right to know that they are being researched, the right to be informed about the nature of the research and the right to withdraw at any time (respect for their autonomy). Participants were informed that their participation was voluntary, and that the researcher follows the rules of confidentiality and anonymity, (Flood, 2021). For that reason, pseudonyms were used and identifiable names such as the name of the organisation was anonymised to further protect confidentiality of the participants under study.

## **Sampling and data collection strategies**

A purposive sample of twenty-four SUs from a BME background with a diagnosed mental illness. The criteria for the study were that the participants would need to have been in receipt of services from the NLMHT for 1 year or more as an inpatient or in the community. That they had been selected following discussion with their CCs on their suitability (due to their vulnerability) to take part in the study. They needed to be either Black British, Black African, Black Mixed race or Black Caribbean. This was determined following peer review by NoCLoR.

The CCs from 6 Community Mental Health Teams (CMHTs) identified participants from their caseload who met the criteria. Those SUs were asked by their CCs if they were willing to take part in the study. The sample included both male and female SUs between the ages of 21 -61.



Reed and Procter (1996) suggested that sample sizes in qualitative research are often small and the sampling is often purposive rather than focused on statistical principles such as randomisation.

The data was collected using a semi structured interview schedule. The duration of the interviews were 30 to 45 minutes and occurred in a room within the CMHT bases; however, 3 participants were not able to attend at the CMHT base therefore the interviews were conducted at their homes.

### **Piloting the research instruments**

Once completed the interview schedule was sent to the manager of one of the local SU groups to give her comment. Also, the interview schedule was sent to the Lead Nurse for the acute service for her comment. Both reported that the structure and the questions in the interview schedule were appropriate.

### **Analysis**

Each of the tape recordings were listened to in their entirety. The tapes were listened to again to ensure the essence of what the participant had said was captured. To maintain accuracy the tapes were replayed at certain points during transcription.

The transcribed interviews notes were read to make sense of the data using Giorgi (2009, 1985) systematic method. At that point words and phrases were being highlighted with the premise to group similar words and phrases to begin the process of identifying emerging themes

### **Results**

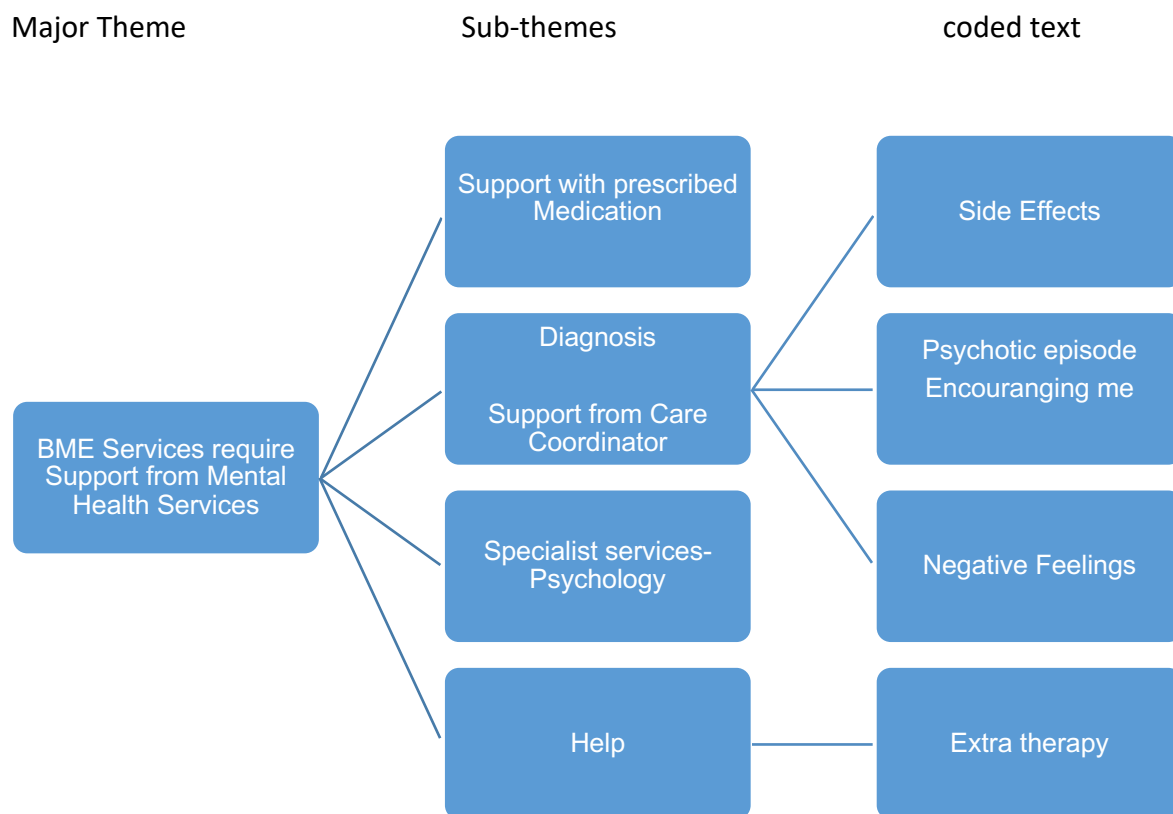
The next stage includes consideration of the results of the study. The analysis including identification of sub-themes and then linking them to major themes identified as seen in Table 1.

Themes	Subthemes
<p><b>BME Service users require support from mental health services</b></p>	<p><b>The need for suitable housing.</b></p> <p><b>The need for specialist services</b></p> <p><b>BME Participants had to wait for varying periods of time before accessing specialist services-Timelines.</b></p> <p><b>Involvement in care plan:</b></p> <p><b>Support from the Care Coordinator and/or the Mental Health Team.</b></p> <p><b>Information about illness and treatment options</b></p>
<p><b>Participants from a BME background would like to find gainful employment</b></p>	<p><b>BME participants experienced being stigmatised in their attempts to find work.</b></p> <p><b>BME participants require extra support in returning to work.</b></p>
<p><b>Recognising signs of relapse</b></p>	<p><b>BME participants established some trigger factors that can cause them to relapse.</b></p> <p><b>Learning from previous experience of being unwell.</b></p>
<p><b>The need for help with taking medication and medication concordance</b></p>	<p><b>BME participants link taking medication as a major part of their recovery.</b></p> <p><b>BME participants highlighted the negative effects of prescribed medication.</b></p> <p><b>Some BME participants experience weight gain as a side effect of medication.</b></p>
<p><b>Service users from a BME background experience stigma</b></p>	<p><b>Some BME participants linked the stigma they experienced as coming from the wider society.</b></p>

<b>Hope</b>	<p><b>Service users from a BME background demonstrate resilience.</b></p> <p><b>Spirituality</b></p>
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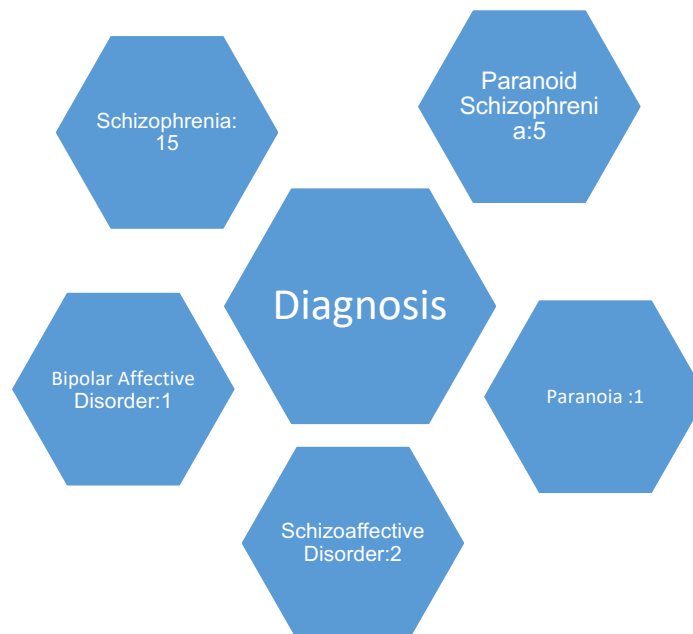
**Table 1: Breakdown of major themes and sub-themes following data analysis.**

Figure 1 (below) gives a breakdown of how the coded text were grouped together to form the major theme—BME services users require support from Mental Health Services as seen in table 1 on page 11.



**Figure 1: Breakdown of coded text**

Figure 2 below reflects the type of mental health diagnosis and the number of participants per diagnosis. 15 participants had a diagnosis of Schizophrenia, 5 participants were diagnosed as Paranoid Schizophrenia. 1 participant was diagnosed as Paranoia, 2 participants were diagnosed as schizoaffective disorder and 1 participant was diagnosed as Bipolar Affective Disorder.



**Figure 2: Participant diagnosis**

The main themes derived from the participant data are outlined and discussed below:

## **Theme One: BME Service Users require support from mental health services**

In this study when the participants were asked about their main needs, several of the participants had a resounding response - 'support'. Notwithstanding, whilst the term 'support' could be quite broad, each of the participants were specific in the type of support they required. This theme comprised 6 subthemes:

### ***The Need for Housing***

When asked about their main needs some of the participants cited housing as one of their main needs. Nathan stated:

*I used to live in supported accommodation but now I have got my own flat, so I don't need to get that much support anymore. I just come for blood test and stick to appointments that's it really (Nathan, 29yrs, male, schizoaffective disorder).*

Mary had a similar view and cited housing and benefits as her main needs. Mary said:

*Just things like housing and benefits just things like housing and benefits really (Mary, 29yrs, female, Schizophrenia).*

Some of the participants including Robert wanted help with his housing situation but had not received it.

Robert stated:

*Both mental health/physical. I need support with my request. I need support with housing...when I requested to move, I did not receive it, instead they start giving me medication. So, I didn't receive what I asked for. I was concern about where I was living, they allocated me to a doctor. They say it would take a long time... I am talking to social services. I am still in the same place I am still waiting (Robert, 43yrs, male, Schizophrenia).*

The concept of 'social isolation' was discussed by some of the participants in this study. Ali talked about being lonely and agreed for others to move into his flat. The impact of his actions related directly on his housing situation, his mental health and personal safety. Ali stated:

*Obviously I have issues to deal with drugs because I'm on drugs as well but I have come off drugs... I have lost my accommodation and because basically I was letting the drug dealers in. Yes, because I was lonely, so I have let them in and .... I'm Muslim been doing drugs, but I have not taken any drugs for the past week (Ali, 49yrs, male, Schizophrenia).*

### **The Need for Specialist Services**

Some of the participants in this study identified specialist services such as psychology and the drug and alcohol service as an area of need. In thinking about this Andrew commented:

*... yeah psychology and drug and alcohol awareness if I start using again they promptly tell me to come to (xxxx-drug and alcohol service) ... because when I talk about things ... I feel like I don't have to carry a weight. So...you know what I mean, to get over their mental health and the stress of day-to-day life people passing and things in the family and then when I go to psychology all of that sort itself out, I can let it all out you know what I mean yeah those are the main things. (Andrew, 31yrs, male, Schizophrenia).*

### **BME Participants had to wait for varying periods of time before accessing specialist services-Timelines.**

It appears some BME SUs had to wait a considerable amount of time before getting help from psychological services. Luke stated:

*It's more psychodynamic so it's more talking therapy and it's the first time I have had it on a one-to-one and I find that it is helping... going through a lot of things that have affected me in the past. ... I have not managed to deal or to get through some issues, so I think not only me but that a lot of people... don't know what services are out there. I think the more people that get this help... being in hospital some people never ever get out of that loop...(Luke, 34yrs, male, schizoaffective disorder).*

The participant above highlighted the help he is now receiving from psychology. There seemed to be a suggestion that talking through issues with a psychologist helped tremendously.

### ***Involvement in care plan***

Collaborative working is essential in the care planning process as it ensures that the BME SU recognises, that they are involved in the process. Engaging in such a collaborative process will allow SU needs to be identified and be provided by Mental Health Services. Some of the responses from the BME participants seem to suggest that the participants were not participating fully in their care planning. Gloria described her experience of attending her care plan meeting and said:

*There is a lot of talking to you and it's a lot of talking at you and if you try to express yourself it's like you are being confrontational, but you're not, you are just trying to explain yourself with what you are going through and how you feel (Gloria, 43yrs, female, paranoid schizophrenia).*

However, Grace stated:

*When I keep well, I realise is the consistency with how the NHS has structured my care because... I tend to feel better ... when my Care Coordinator visit or like the therapy, I am getting now on a weekly basis...but I find like if it's not there for long time, I just feel like I am going down! (Grace, 51yrs, paranoid schizophrenia).*

With specific reference to participants' experiences concerning the use of mental health services in the Trust, all the participants were happy with the care that they received. Nonetheless, some of the participants seem to link any discrimination/stigma to come from external agencies such as the Police, Criminal Justice System, Employment and the wider society. Paula felt wronged by the police, because a record of an offence was registered on the Disclosure Barring Service check (DBS). This meant that checks show that she has a record of an offence. She felt that as she was given a caution it should not have been placed on her record, as it impacted negatively on job applications. Her exact words were:

*They say they will call you back and they never do (Paula, 47yrs, female, Schizophrenia).*

Charles stated:

*So as a black man I think I have not experienced any racism, I think they are fair (Charles, 42yrs, male, Paranoid Schizophrenia).*

Notwithstanding, in this study most of participants were able to articulate what their needs were and how they were being met, even though not all participants felt their main needs were that of support.

### ***Support from the Care Coordinator and/or the Mental Health Team***

All the BME participants placed great emphasis on meeting with their CC and recognised that the CC was central to their care as they can call upon the CC to help them manage a range of situations. Grace said:

*In general, my mental health but because over the years I have had a lot of side effects from the medications like mood and sometimes do still get depressed I get support from my care coordinator (Grace, 51yrs, female, paranoid schizophrenia).*

George stated:

*My main needs were to sort of get a recovery plan of getting better, yes a recovery plan, recovery plan getting better (George, 36yrs, male, Schizophrenia).*

### ***Information about illness and treatment***

Most of the participants were able to articulate what their diagnosis was and what information they were given about their illness. However, the participants displayed different



levels of understanding of what the term schizophrenia meant. Some of the participants identified with the term as it is portrayed in the media. Paula stated:

*They were not very clear, but I also read the letter that was written about me that said I had a condition, because I have been suffering from a condition for ten years now because every time I came in it's a different diagnosis. When I was here last time, they said that I am suffering from Schizophrenia or something like that (Paula, 47yrs, female, Schizophrenia).*

Paul explained:

*Well the doctor explained to me, that I have a condition, that I am schizophrenic and that I will be on medication, they gave me a pack telling me what the medication does what it will do and how to take it and explain to me my rights and stuff (Paul, 38yrs, male, Schizophrenia).*

The information from the BME participants suggest that they were aware of their diagnosis, but some needed further clarification in understanding how the illness presents in terms of symptoms and treatment options.

## **Theme Two: Participants from a BME background would like to find gainful employment.**

When asked about their main needs some of the BME participants identified being employed as a need. A number of the BME participants talked about the negative experiences they encountered in their attempt to gain employment. Others felt that they required extra support to return to work. Those two areas have been broken down into subthemes

### ***BME participants experienced being stigmatised in their attempts to find work.***

Paul used to be in employment on a part-time basis. He said:

*Is that aspiration to get back to work... also in catering I have done level 2 supervisory role. A lot of people they go into hospital they started wondering why nothing is going*

*right for them but they don't realise, so my support team encourage me that I could do things for myself, If I can one day support my family I want to get a move (Paul, 38yrs, male, Schizophrenia).*

Another participant spoke about her experience in a sheltered work area when she did catering. She was concerned that the lady who taught the group did not follow proper procedure. The participant linked that behaviour to the negative views of people who have a mental illness. She described the teacher's attitude as 'slapdash'. Gloria stated:

*I feel as though they don't put their whole heart into it, they just want to give people a slapdash course. To me...if you're working in a different environment you would have to wear the hair net because if any hair went in the customers food you would be in trouble (Gloria, 43yrs, female, paranoid schizophrenia).*

The participants above experienced stigma in their efforts to find work. This has no doubt impacted on them in several ways including social, financial, and psychologically. The experience has hindered their progress in reaching a place of fulfilment.

### ***BME participants require extra support in returning to work.***

A number of the BME participants spoke about their desire to return to work but also recognised that they needed extra support in returning to work. In particular, some participants cited a less intense environment to enable them to adjust after a period of sickness. Some participants felt that engaging in leisure activities such as playing the guitar or going to the gym gave them structure which allows them to build their confidence in preparation to return to work. Ryan stated:

*I will say that she is a role model, she encourages me to participate in things like for instance... my last job was two years ago and since then I have been unwell three or four times and so I just wanted to get back to work, but right now I am not in the right place... and it's my Care Coordinator that really showed me that I have to focus and concentrate in my mind re-educating my mind. Find hobbies, find interest first... I have just got to look at it from my perspective (Ryan, 40yrs, male, paranoid schizophrenia).*

Grace, one of the BME participants placed a huge emphasis on the need to be employed. However, she felt that for those who have attempted to find work they faced certain challenges and described the SUs as “going around in circles”.

Those participants who had been employed contended that they could not always be at work due to the frequency of their relapse. This meant that they had to take time off work. Luke stated:

*...at the time I was working at HMV records service I would lose sleep I would have strange ideas, there are times I needed to take time off work because I... used to get this really bad feeling at times (Luke, 34yrs, male, schizoaffective disorder).*

### **Theme Three: Recognising signs of relapse**

The BME participants were asked about their needs when they experienced a crisis in their mental health condition. Some of the participants talked about factors that caused them to relapse and also areas of learning which they felt has helped them in the management of their illness.

Trigger factors that can cause them to relapse

A number of the participants were able to recognise signs of relapse. There were those who remembered what happened when they first became unwell. A few causes were cited including drug induced psychosis. Guy said:

*I normally suffer from schizophrenia and paranoia and that the crisis is that I get anxious and paranoid... yeah but when I'm taking the tablets yeah, I notice and sometimes getting panic attacks, ... I noticed when that happens, but the tablet is really umm. Before I did not think that the tablets were helping I used to think it was my own self but now I realise when I don't take it I get those kinds of feelings and now when I take it everything just seems alright so it's more manageable (Guy, 23yrs, male, Schizophrenia).*

Paul stated:

*Because the reason I was unwell is because I was taking drugs...after all it was the drugs I was taking. When I take the drugs, I got paranoid, ... that's when things starts going wrong, and not being able to sit down with my mum and tell her this was what was going on.... (Paul, 38yrs, male, Schizophrenia).*

*You see before I was on heroin...that was what used to trigger my symptoms so I'm off heroin now so that's why I think I have been so well (Charles, 42yrs, male, Paranoid Schizophrenia).*

### ***Learning from previous experience of being unwell.***

It can be suggested that the service user is best placed to recognise their relapse indicators either by learning or by observational skills of the mental health staff, family and friends.

Jacob had to contend with anxiety attacks and spoke about ways to alleviate it when the anxiety attack happens. In thinking about the question on recognising relapse signature

Jacob said:

*When I'm having an anxiety attack, I usually just have a warm shower or listen to music or anything to put my mind at ease (Jacob, 24yrs, male, Schizoaffective Disorder).*

Paul also talked about what triggered the symptoms of his illness and stated:

*If that happens, I can always ring my care support team they will always help me, or I can make my way to hospital...so it does not go too far where they come and pick you up and take you instead you take yourself (Paul, 38yrs, male, Schizophrenia).*

Another participant (Andrew) from a BME background, had a fifteen-year history of being involved with the mental health service. He narrated his views on drug misuse and recognised this as his relapse signs. He had several admissions into hospital following periods of substance misuse.

*I'll be honest with you I use a bit of drugs now, but I don't relapse, obviously I'm a bit older now so when you're younger your mind is not as strong... now as you get older you much*

*more in control. I'm more mature now am 31... I understand how people say they used drugs in order to get away... but obviously I don't use it to that extent where I cannot handle myself...It's just like having a drink, a bottle of wine with your dinner that's how I look at it (Andrew, 31yrs, male, Schizophrenia).*

Participants from a BME background discussed their learning from the experience of being unwell. They used that experience to inform how to manage their mental health.

#### **Theme Four: The need for help with taking medication and medication concordance.**

The use of medication is a process that have been used over many years to treat the symptoms of a diagnosed mental condition. The participants from a BME background identified taking medication as one of their main needs.

#### ***BME participants link taking medication as a major part of their recovery.***

Support while taking medication was cited as an area of need by most of the participants. There was also a recognition by the BME participants that medication had a major part to play in their recovery.

Paula talked about the calming effect the medication had on her and said:

*I must say medication is the first thing because it help to calm me down and it help me to relax and made me aware that I am unwell and that I need to take it but also looking positively into life because I don't want to look at it as if it is something that is stigma around mental health (Paula, 47yrs, female, Schizophrenia).*

Emma had a similar view and said:

*Taking my medication and then I will not become sick. That is if I don't take my medication then I would be sick yeah (Emma, 31yrs, female, Schizophrenia).*

The above participants noted the benefits of taking prescribed medication and linked it to their recovery and ongoing optimism.

***The BME participants highlighted the negative effects of prescribed medication.***

One reason for poor compliance with medication was the belief that “nothing is wrong with me”. Paul explained that as he was well all his life, it was difficult to comprehend how could something like mental illness happen to him. However, he got to a place of acceptance and belief that the medication he was taking had a role to play in keeping him well.

*I have been fit all my life so I didn't really realise that it could happen to me so when it first started, I wasn't really like taking the medication... so I was a bit in denial ... but over the years I have come to realise that it is an illness and it can be treated and with the right medication. I found ... the best thing is to take your medication and get on with your life like my mum she is diabetic so for her all of her life she has to take medication but... I did not believe that thing could happen to me and stuff like that and I did not really like this side of being unwell (Paul, 38yrs, male, Schizophrenia).*

Harry linked the cessation of the negative symptoms he experienced with taking medication. He said:

*When I do become unwell, I disappear you see but it stopped 12 years ago maybe the disappearing has stopped it may come back, again I don't know if I stop taking my medication (Harry, 61yrs, male, Schizophrenia).*

Dominic talked about the side effects he experienced while taking prescribed medication and said:

*... I have been having side effects, that's awful I feel drowsy in the morning...they are looking into (Dominic, 30yrs, male, Schizophrenia).*

Roger who was diagnosed with Bipolar Affective Disorder described what it was like when he was in the depressive cycle of the illness. He explained that he would rather ‘rough it out’ rather than take prescribed medication.

*They say it's when I stop taking the medication, because many times I have tried stopped taking the medication rough it out sort of thing, because I try to wean myself off medication (Roger, 41yrs, male, Bipolar Affective Disorder).*

Another participant experienced side effects of taking psychotropic medication. He also had a view on what he thought was causing his mental illness.

Robert stated:

*At the same time, they send me to hospital. I am an African man I see a woman in my flat, those things disturbing they say they can stop it by giving medication... I am worried about my weight, I was sleeping a lot, my heart is beating from me. If it is witchcraft medication won't get rid of it. It is not a sicknes (Robert, 43yrs, male, Schizophrenia).*

The above participants discussed how experiencing side effects of medication impacted on their daily living. However, there was a tone of joint working with the professionals in finding the medication regime that suited each individual participant.

### ***BME participants experience weight gain as a side effect of medication***

Several of the BME participants expressed reasons why they stopped taking their medication. Some suggested that they experience severe debilitating side effect effects from medication. There were descriptions of physical effects such as weight gain, feeling drowsy and stiffness in joints which made walking difficult.

Luke highlighted that he stopped taking his medicines due to the many side effects he experienced. Luke said:

*...I was working as well in a part-time job...they were giving me tablets and I was not aware what effect they were having on me. The first one was making my tongue hung out ... I could not breathe and other times I was on olanzapine it made me put on a lot of weight*

*on my face blew up, I could not feel anything emotionally... and I did not know what was going on (Luke, 34yrs, male, schizoaffective disorder).*

Similar to Luke, Grace cited one of the side effects of medication as weight gain. She said:

*I think I use to be able to do things but since my illness I find that I am not able to do it anymore. That gets me down I think it's the medication. I am slowed down, and my life is totally..., so that gets me down. I think it's to do with the medication. Because of the medication ... I gained about 8 stone..., I lose it and then I end up putting it back on, really, it's a struggle (Grace, 51yrs, female, paranoid schizophrenia).*

The participants above struggled to maintain a healthy weight which was a result of taking psychotropic medication. This would suggest an area of need for the BME participants to maintain a healthy weight.

#### **Theme Five: Service Users from a BME background experience Stigma**

The participants drew a parallel between those who work in mental health and those who live in the wider society. The participants suggested that those who work in mental health understood the illness, therefore they did not feel stigmatised by mental health workers.

#### ***BME participants linked the stigma they experienced as coming from the wider society.***

The participants explained that the stigma they encountered came from the wider society as there was a misunderstanding of mental illness. The participant felt that the stigma they experienced was compounded as mental illness has been portrayed negatively in the media.

Paula described how stigma of mental illness has affected her and said:

*I don't talk about my mental health to anybody unless it is the medical profession or somebody who need to know because of certain law or something cause I..., don't feel comfortable that they would keep it as secret as I don't think they will understand that somebody can have mental health and still work or still do anything productive. It is like they are sort of doomed and they are people who have no use in society, so I have that*



*feeling in me, but I don't speak about it to my friends or colleagues or anybody (Paula, 47yrs, female, Schizophrenia).*

Luke talked about his experience as a black man and felt that the stigma he faced was not from the mental health service but in the community.

*...and I don't think it's really an issue personally... but I think when you are out and you're trying to get back in the community, even sport because anything that young people did when you first become mentally ill the worst thing is you lose your love of things; you lose your passion because you think that you cannot do anything (Luke, 34yrs, male, schizoaffective disorder).*

Ali had a strong belief in his faith however he stated that he did not attend a place of worship as he felt his misuse of drugs made him not worthy of being with fellow believers.

*Yes, I am Muslim but that sometimes because of the situation I have been in I wasn't stopped physically from going but it was just the company I was keeping stopped me from going so I have not been going (Ali, 48yrs, male, Schizophrenia).*

Another participant Gloria linked the voices that she experienced as an invasion of her body and saw it as a stigma.

### **Theme Six: BME Participants had Hope for the future.**

The participants discussed their journey of recovery and expressed how hopeful they were for the future. Whilst hope was the major theme, the following are the corresponding subthemes.

#### ***Service Users from a BME background demonstrate resilience***

The participants who were from a BME background talked about how their illness had affected them and how they saw their future. Some talked about personal strength, others talked about religion, and others talked about family and friends.

Paul contended that a weight was lifted from him when he was able to speak to his mother about how his illness was affecting him and said:

*especially black people you know, black people don't like saying it in front of their mums you know, you know it's like a stigma... but when you finally know the truth or telling the truth your life suddenly become better it is like something lifted. Yes, the medication does help but staying off drugs and doing the right thing you know. Things such as I want to settle down, and I think I don't want to go back to taking drugs I just want to be independent (Paul, 38yrs, male, Schizophrenia).*

Equally, Charles attributed mental illness and as being a stigma that he wanted to leave behind and focus on his hope for a positive future. Charles stated:

*You see ... mental illness, yes I was ill once but I don't accept that I am ill now... I think you can get better... I am as best as I can be. I am not going to go back to the old me before I got ill, I am the new man now (Charles, 42yrs, male, Paranoid Schizophrenia).*

Leo expressed his belief and said:

*There is Hope. Faith and Hope this is about my Christianity, that's worth holding onto that isn't it? (Leo, 41yrs, male, Schizophrenia).*

Despite what the above BME participants are going through they demonstrated resilience with the hope of getting better.

### ***Spirituality***

The narratives offered by the BME participants suggested that spirituality played an important role in their wellbeing. That having a religious belief gave them comfort to know that all will be well if they only believe and have an acceptance in the good that has occurred in their lives.

Roger had a strong belief in his faith and felt that was more beneficial than taking medication.

He stated:

*Actually, in my own opinion the drugs don't really do it for me, it's when I go for prayers and that...I just go to a Pentecostal church now and then (Roger, 41yrs, male, Bipolar Affective Disorder).*

One of the main features of the recovery approach is instilling hope in the lives of those who have a mental health problem. The BME participants talked about how their illness has affected them and about their future. Some talked about personal strength, others talked about religion, and others talked about family and friends. When asked about what has kept him well, Ali was able to make links with his faith. Ali stated:

*Obviously when I went into hospital, I was ill so I would not say that the medication I received was totally responsible for getting me better...I think it's not just the medication that keeps you well, I think it's time as well... and obviously I am a Muslim, so my Lord use me as well. He has already told me that in the dream ... whenever you need healing as long as you make an effort, he's my Lord. He created me and you also. (Ali, 48yrs, male, Schizophrenia).*

Paula also talked about her Christian walk and how she was conflicted about the mix between medication and prayers.

Paula stated:

*Also being a Christian because I am a born again Christian and I read the bible most of the time so that helps me a lot, so I am always just there just hoping. I don't want to get ill again you know because I thought I would just leave the medication and just get well by myself by just praying but it didn't work for me... I took my medication and since 2011... I have been well, so I see it works so I don't want to feel like I am under pressure to leave any medication or anything (Paula, 47yrs, female, Schizophrenia).*

Hannah in answering the same question was adamant that she had not benefited under the mental health system and stated:

*Well Hinduism and Buddhism, I've been to the Hari Krishna Temple in Tottenham Court Road... (Hannah, 43yrs, female, Schizophrenia).*

The above narratives suggest that the participants spirituality played an important role in their wellbeing. That having a religious belief gave them comfort to know that all will be well if they only believe and have an acceptance in the good that has occurred in their lives.

## **Summary of Results**

The participants were able to identify their areas of need and also expressed the negative impact of their illness on their lives. That included the side effects of the medication, the lack of opportunity to be employed and the stigma they faced in the wider community. The participants demonstrated their appreciation for the role of their CC and the help they received from the mental health service. The participants showed an awareness of how mental illness can be portrayed negatively in the media. By association, one of the participants did not talk openly about her illness as she feared reprisals by the wider community/public. Nevertheless, the participants were able to demonstrate that with the right support they were able to make plans for a better future.

## **Discussion**

Six themes and sixteen subsequent sub themes were identified in this study and will guide the discussion. Theme one was centred on BME participants need for support from mental health services. In terms of support the findings highlighted that housing was one of the main needs of the BME participants. It has been suggested that persistent poor housing problems can lead to poor mental health, (Pevalin *et al.*, 2017).

Ali (pseudonym) talked about being lonely and allowed others to stay in his flat. Unfortunately, those who stayed in his flat were dealing in illicit drugs rendering him to feel unsafe in his own home. He was able to alert his CC regarding what was going on who ensured that he was moved to more suitable accommodation.

Holt-Lunstad *et al.* (2015, p. 227), theorised that living alone, having limited social network ties, and having occasional social contact are all indicators of social isolation. Whereas social isolation can be an objectively quantifiable variable, loneliness is a subjective emotional state. Loneliness is the awareness of social isolation or the subjective experience of being lonely and thus encompasses subjective measurement.

The need for specialist services in particular psychology and drug and alcohol services were cited by the participants as another main need. Specific interventions typically offered in early intervention psychosis (EIP) include individual cognitive behavioural therapy (CBT), family therapy and carer interventions, medication in the form of a low-dose antipsychotic regime and social support around education, employment, and housing. Interventions such as these are recommended in the guidance for schizophrenia published by the National Institute for Health and Clinical Excellence, (NICE; 2014, 2010).

Memon *et al.* (2016) conducted a research study with BME SUs to establish perceived barriers in accessing the mental health service and how the services can be improved. Participants identified two broad themes that influenced access to mental health services. First, personal and environmental factors included inability to recognise and accept mental health problems, positive impact of social networks, reluctance to discuss psychological distress and seek help among men, cultural identity, negative perception of and social stigma against mental health and financial factors.

Second, factors affecting the relationship between SUs and healthcare provider included the impact of long waiting times for initial assessment, language barriers, poor communication between SUs and providers, inadequate recognition or response to mental health needs, imbalance of power and authority between SUs and providers, cultural naivety, insensitivity

and discrimination towards the needs of BME SUs and lack of awareness of different services among SUs and providers, (Memon *et al.*, 2016, p. 3).

Since the inception of the Care Programme Approach in 1990, the CC has been identified as having a pivotal role in managing the care of SUs with mental health problems. Whilst much has been written about the role of the CC, SUs themselves rely on that individual to offer the support they require in their journey through mental health service.

Patient participation has been viewed as a means to enhance self-determination and empowerment of the SU. The notion of shared decision-making (SDM) as discussed by De las Cuevas *et al.* (2012) is a clinical model that promotes an interactive communication process where healthcare professionals offer their evidence-based technical knowledge, established on population averages, while patients provide information about their own preferences, values and concerns with respect to the available diagnostic or treatment options to reach a consensus on the decision (Deegan and Drake, 2006).

The term stigma has been described as ‘a severe social disapproval due to believed or actual individual characteristics, beliefs or behaviours that are against norms, be they economic, political, cultural or social,’ (Lauber, 2008). The basis of which seem to be a lack of knowledge about mental health, fear, prejudice and discrimination. Stigma in mental health has been a long-standing issue. More recently an attempt to raise awareness by the ‘young royals’ Prince Harry, Prince William, and Kate Middleton helped to inform the public through their ‘*Heads Together*’ campaign about mental illness.

The evidence in this study showed that most of the participants had difficulty in finding work. Two reasons were given: firstly, the lack of understanding about mental health issues in the workplace, and secondly discrimination against those who had a mental illness, (Flood, 2021). Cartwright *et al.* (2017) inferred that people with SMI are disproportionately unemployed. This was also found to be the case by Bond and Drake (2008). One BME participant Gloria (pseudonym) experienced such stigma while attending a sheltered workshop. She felt that the teaching was ‘*slapdash*’ and linked it to negative views of people with mental illness.

Due to the stigma the participants encountered some felt unable to tell their employers or other work colleagues that they had a mental illness. The experiences of the participants in this study were upheld by Thornicroft (2006a, 2006b) who found that there was strong indication that those with mental health problems find it difficult to gain access to and retain employment. It has been suggested that people with SMI in the United Kingdom have an unemployment rate of 61-73%.

Theme three concentrated on participants recognising their relapse signature. The SU is best placed to recognise their relapse indicators. This occurs either through their own learning from their experiences when unwell, or by observation of mental health staff, family, and friends. However, Eisner *et al.* (2018) noted that basic symptoms may be potent predictors of relapse that clinicians miss and contended that, the best way of identifying pre-relapse basic symptoms was a verbal checklist asking specifically about these experiences.

The authors noted that the use of a basic symptoms' checklist in clinical practice, in conjunction with an existing checklist of conventional early signs, may yield a richer relapse signature. It was interesting when the researcher asked: how do you describe a mental health crisis and what action is taken when that happens? The BME participants were able to articulate answers such as '*crying, don't want to do anything, I stopped taking medication, hears voices, tell my mum and my brother*'. One participant stated, '*people see the changes in my mood*'.

Richards *et al.* (2013) postulated that we need to accept that expertise in health and illness lies outside as much as inside medical circles and that working alongside patients, their families, local communities, civil society organisations, and experts in other sectors is essential to improve health.

Substance misuse was also found to contribute to at least six of the SUs experiencing a relapse. Substance misuse among psychiatric spectrum disorders is widespread (Di Forti *et al.* 2019; NICE, 2016). It was estimated that in the United Kingdom a third of patients with SMI have an active substance use disorder including schizophrenia, mood, dissociative, and personality syndromes ( Das-Munshi *et al.*,. 2020; Department of Health, 2006).

One of the BME participants, Paul (pseudonym), recognised that he became unwell because he took drugs. He described that he got paranoid after taking drugs which usually led to hospital admission. It was interesting to hear how another participant Andrew (pseudonym), described his understanding of substance misuse, and compared the effects on his mind as not being strong when he was younger, but now fifteen years older he feels more in control.

Much research has been done in the use of medication resulting in the formulation of newer drugs which profess to have less side effects making them more tolerable for the SU . However, several BME participants expressed reasons why they stopped taking their medication. Some suggested that they experience severe debilitating side effects from medication. There were descriptions of physical effects such as weight gain, feeling drowsy and stiffness in joints which made walking difficult. There were also descriptions of psychological effects from taking medication. (Mwebe, Volante & Weaver, 2020, p. 3).

Accordingly, people who use mental health services need help with managing their diet and food intake. A mixture of diet and exercise would be key in supporting SUs in their mental health journey. Charlton (2015) explained malnutrition and mental health disorders as a chicken and egg scenario. Does the presence of mental illness influence eating behaviours and result in an insufficient intake, or conversely, does a poor nutritional status impair mental function and lead to worsening of symptoms? The overwhelming body of evidence suggest that malnutrition predicts adverse clinical outcomes (Slattery *et al.* 2015; Jan-Magnus *et al.* 2011) and requires innovative strategies to address this problem in practice.

Theme five concentrated on the BME participants experiences in using the mental health services in the Trust; particularly if they felt discriminated in anyway. All the participants stated that they did not experience discrimination in the care they received in the Trust. They seemed to link any discrimination/stigma as originating from external agencies such as the Criminal Justice System, Police, Employment, and the Wider Society. That was the experience for (Paula) who was given a police caution several years earlier as it hampered her ability to find employment.



Theme six highlighted that whilst there have been some negative experiences namely, stigma and discrimination the participants were filled with hope for the future. Going through a major illness such as mental illness enables the individual to build resilience. This is the substance of how well one adjusts to the devastating effects that come with such an illness including loss of employment, breakdown in relationships, financial concerns, housing issues.

In this study the BME participants identified with a number of different factors which were aligned to the concept of hope. Some talked about personal strength, others about religion and others family and friends. It was clear that they all felt the intangible sense of knowing that these areas played a major role in keeping them well. Paul (pseudonym) discussed how he hid his substance misuse habit from his mother. He described it as being a stigma in the black community. However, when he was open with his mother he felt like a '*weight*' had been lifted from him. This seems to suggest that a positive mental attitude towards one's illness enhances their chance of recovery (Sagan, 2015).

Ali (pseudonym), who was of the Muslim faith felt that his substance misuse habit was not in keeping with his faith. Whilst he had a strong belief, he did not attend a place of worship, as he felt the misuse of drugs made him unworthy of being with fellow believers. Ali (pseudonym) felt shame and embarrassed about his substance misuse behaviour. Other participants talked about their Christian belief in their journey to keeping well. However there was a recognition by the participants that it was a joint effort with medication and their faith that had worked.

The findings showed that the needs of the BME participants were met to some extent. For example, all the participants emphasised the value in meeting with their CC. However, on issues such as housing, specialist services and medication the BME participants stated that they needed further support. Similar findings have been put forward by Islam, Rabiee & Singh (2015).

The participants understood the term CPA, but not all participants believed that they were involved in the process. However, the BME participants also believed that their spiritual belief and medication needed to go side by side as they placed equal importance in both. Research

has shown that culturally spiritual beliefs feature quite highly within the BME community (Tuffour, 2020; Hays and Aranda, 2016; Keefe *et al.*, 2016).

## Limitations

A limitation in this study was the concept of 'insider researcher' (Berkovic, 2020; Tuffour, 2018, p. 3) which came to the fore, as I was in a senior role in the Trust and was mindful of the fact that I had to follow all the appropriate steps to carry out this study, from accessing SUs as participants to conducting the semi structured interviews. In addition, as an employee and a mental health nurse (MHN) the participants could have viewed me as a CC rather than a researcher. That was evident when one of the participants asked whether my meeting with him would be a regularly occurrence. I explained what my role was as part of the research study.

Whilst the objective of the research study was to elucidate information from BME SUs about their experience, I was mindful that the participants could have viewed me as part of '*the system*' and felt obliged to say what they thought was appropriate especially on sensitive issues such as race and culture. Equally, it would have been useful to hear the views of staff and carers in meeting the needs of the BME SUs, however as the remit of this study did not include the views of staff or carers, it is suggested that further research is necessary as both are integral in providing and managing the care and support that the BME SU requires.

## Conclusion

The results of this study showed that concepts such as needs, user involvement, ethnicity and race were explored. The results also highlighted the vulnerability of SUs in mental health. A discussion regarding the participants' views on their perception as to whether their needs were being met occurred within the study. In terms of support, the results highlighted that housing was one of the main needs of the BME participants. The need for specialist services in particular psychology and drug and alcohol service were cited by the participants as their main needs.

Other areas highlighted in this study was the need for support from the CC and BME participants requiring information about their illness and treatment options. Additionally, the findings showed that the BME participants required extra support in returning to work. Notably, medication concordance was a subject of discussion in this study. The results highlighted that BME participants viewed medication as a means of support. The participants noted that they experienced side effects from the prescribed medication.

The results also indicated that the BME participants faced discrimination from the police, criminal justice system, employers, and the public at large. The implications for practice and the need for further research, were key aspects in the findings as they are relevant to Mental Health Staff, policy makers, stakeholders, voluntary and spiritual organisations. This would ensure a well-coordinated programme of care within mental health services in meeting the needs of the BME SU.

## **Recommendations:**

The following recommendations are grounded in and derived from the evidence and results of this study:

- Training programme for the police and other social care and mental health professionals to enhance skills when dealing with someone with a SMI.
- Mental Health Professionals to continue to challenge discrimination through social media campaigns, video, and publication.
- Recommendation to the Chief Nursing Officer and the Nursing and Midwifery Council regarding implementation of 'Consistency' as the 7th C.
- Transformative approach in the negotiation and regular review of the Care planning process.

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