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FUNCTIONAL NEUROLOGICAL DISORDER: A FAITH AND
CULTURAL PERSPECTIVE.

Section A: Is the UK Healthcare System Struggling to Meet the Needs of
Culturally Diverse Populations? An Integrative Review of Cultural Competence
in NHS Services

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Summary of the Major Research Project

Section A:

A systematic review of research that can contribute to knowledge of understandings and use of Cultural Competence (CC) initiatives in UK healthcare settings. A search of databases found ten studies. The findings were integrated to identify six themes relevant to understanding the term CC and CC initiatives. The review highlights inconsistencies in conceptualisations of CC and problems were found in the implementation of CC initiatives which often go unmonitored.

Section B:

An empirical paper exploring the role of family, faith and culture in Black and Asian individuals experiencing functional neurological symptoms. Seven semi-structured interviews were conducted and analysed using Interpretive Phenomenological Analysis (IPA). The results indicate that individuals largely understood their symptoms from a Eurocentric medical lens, but that the diagnosis was difficult to come to terms with. Cultural influences such as help-seeking behaviours, symptom and suffering perceptions, upbringing and language were found to play a part in how one experiences FND. Stigma and faith were found to play a significant role in individual's experiences.

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SECTION A

**Is the UK Healthcare System Struggling to Meet the Needs of
Culturally Diverse Populations? An Integrative Review of Cultural
Competence in NHS Services**

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ABSTRACT

Racial health disparities continue to exist despite strong legal and policy frameworks on 'equality' for all. Cultural competency (CCy) has been proposed as a solution to improving health outcomes for culturally diverse patients, however there are no reviews on CCy in UK healthcare settings. This paper aimed to systematically and critically review the extant literature on understandings and use of Cultural Competence (CC) initiatives in UK healthcare settings. Systematic searches were carried out using five electronic databases: PubMed, PsycInfo, Medline, Web of Science and CINAHL and ten papers were reviewed. Results highlight inconsistencies in conceptualisations of CC, with understandings largely concerned with clinicians understanding the patient's culture and meeting their linguistic needs. Problems were found in the implementation of CC initiatives for example, challenges were found with diversity training, knowledge and understanding, recruitment and resources. Promising evidence for a cultural consultation service was found, however, methodological issues limit drawing definite conclusions. Recommendations for future research and practice that monitor and evaluate CC initiatives are recommended.

Keywords: Cultural Competency, Racial health inequity, UK, National Health Service

Introduction

Super-diversity in the UK and ethnic disparities

The past several decades have seen an increase in global migration between nations, leading to rapid social and cultural change. The population of the United Kingdom (UK) is increasingly becoming multi-ethnic and poly-cultural (Vertovec, 2019). As such, the UK has been described to be in a period of ‘super-diversity’, a concept used to describe continuous changing patterns observed in British migration data, reflecting more countries of origin, and entailing multiple ethnicities, languages and religions (Vertovec, 2007, 2019). Vertovec also proposed the term to indicate the production of new hierarchical social positions, statuses, or stratifications, which in turn entail new patterns of inequality and prejudice including emergent forms of racisms and new patterns of segregation.

Super-diversity in Britain creates opportunities and challenges for public sector organizations such as the National Health Service (NHS), as equality legislation in the UK necessitates public sector organisations to deliver high-quality services to all service users (SUs) regardless of their cultural background (HMSO, 2010). Thus, responding to the needs of culturally diverse SUs is one of the most critical areas of reform in public sector organisations (Wilson & Iles, 1999). Accordingly, the NHS is required to ensure their organisational culture meets the needs of SUs equitably (Department of Health, 2005). Yet individuals from culturally-diverse backgrounds have an increased risk of poor health compared with White individuals (Razai et al., 2021). There is a substantial body of evidence indicating that the multidimensional social and economic inequalities experienced by culturally-diverse populations (including the experiencing of racism), make a substantial contribution to racial health inequalities (Chouhan & Nazroo, 2020; Paradies et al., 2015; Williams et al., 2019).

Culture

Culture is a malleable societal construct vaguely referring to a vastly complex set of phenomena (Jahoda, 2012). There have been many attempts to define culture within the literature, producing diverse interpretations, some of which are incompatible with each other. While some define culture in terms of external processes (e.g., Jahoda, 2012), others (e.g., Mironenko & Sorokin, 2018) define culture as encompassing both internal and external processes.

Traditionally, culture has been defined as:

The integrated pattern of human behaviour that includes thoughts, communications, actions, customs, beliefs, values and institutions of a racial, ethnic, religious or social group (Cross et al., 1989, p. 3).

Traditional definitions of culture have held racialised connotations designed to reaffirm the superiority or dominance of one culture to another, based on presumed racial or biological characteristics. Such definitions have led to many oppressive and colonial regimes (Davis, 2020). Given the historical uses of culture, one should be critical of attempts to define culture and the intention in this. Nonetheless, there have been transformations in the use of the term culture. Culture can now be used by groups to establish, reaffirm and celebrate their cultural identity and difference. More recently, Mironenko and Sorokin (2018) defined culture as:

“A multidimensional phenomenon that encompasses processes, products and results of human activity, material and spiritual, transmitted from generation to generation in a non-biological way” (Mironenko & Sorokin, 2018).

“Spiritual” in this sense referred to a culture’s language, literature, art, and science, etc., and “material” to tangible items such as artefacts, with the authors adding that ‘culture’ includes both internal (i.e., individual psyche) and external processes (i.e., relating to constantly

emerging and changing customs and traditions) (Mironenko & Sorokin, 2018). However, despite a turn towards more multiple usages of the term, 'culture', discourses on culture have largely assumed a fixed culture, assuming a homogeneous entity, denying diversity and multifaceted aspects within a cultural group. Given the multifaceted nature of culture, questions are raised about what is being measured when cultural competency (CCy) is being evaluated.

Cultural competence: A complex term

Cultural competence (CC) is a contentious issue, while governmental and health policies strongly advocate for culturally competent (ClyC) services, others advocate for the abandoning of limited notions of CC (Wong et al., 2021). Much like culture, several definitions of CC have been proposed in the literature, with significant inconsistencies in its definition. Currently, there is no consistent definition of CC across healthcare systems (Henderson et al., 2018). In a breakdown of the two terms, 'culture' and 'competence', culture was defined above as something multifaceted, while the Oxford English Dictionary defines 'competence' as, "*The ability to do something successfully or efficiently*" (2020).

Therefore, CC could be described as having the appropriate skills, ability and sometimes experience in matters of 'culture'. From this definition, it may be deduced that being 'ClyC' implies that one has the authenticity in doing, taking part in, communicating, understanding and explaining one's own and others' culture (Davis, 2020). Competence in one's own and other cultures necessitates a perception of culture as adaptive, innovative, and expressive (Davis, 2020). CC definitions, on the other hand, primarily address certain aspects of CC. For example, this is done by focusing on one level of the healthcare system in which CC is perceived to be needed. Other definitions only include acknowledgement of factors impacting on healthcare which are understood to be cultural, without consideration for social

factors which are thought to be central to CC by others. Overall, definitions are largely concerned with the capacity of frontline healthcare professionals (HCPs) to provide ‘cultural’ and appropriate care to people who do not share the same ethnic identity, language, cultural markers or racial categorisation (Jongen et al., 2018). Such definitions have faced criticism for their tendency to oversimplify the complexity of culture and overgeneralise and stereotype people who share similar traits (Liu et al., 2020). This is further fuelled by the lack of consensus about how CC can be achieved. The lack of a clear definition is both a result of and contributor to the complexity in CC interventions and evaluations (Truong et al, 2014).

Dominant narratives on effective CC in healthcare operate on the basis that it is impossible to achieve without knowledge of a patients’ culture and background. Hence, many CC approaches aim to increase practitioners’ knowledge of patients’ cultural background. CC approaches aim to enable clinicians to reflect on their own culture and to identify, respect and act with consideration and humility when relating to people from other cultures. However, none of these definitions refer to the impact of social structures or social factors beyond culture which are implicated in CC (Jongen et al., 2018).

International reviews on CC (Alizadeh& Chavan, 2015; Jongen et al.,2018; Renzaho et al., 2013; Troung et al., 2014) have found inconsistencies in definitions of CC which in turn have an impact on implementation. Additionally, lack of training, self-report bias and lack of methodological rigor and validity for CC models were found to be commonplace. Recommendations for research to objectively measure healthcare provider and patient outcomes, consider organisational factors, re-evaluate training programmes and utilise more rigorous study designs have been made.

The theory of planned behaviour (TPB) (Fishbein & Ajzen, 1975) proposes that intention to change is the best predictor of behaviour. Intention can be influenced by three

internal and external factors: attitude (whether the person is in favour of doing it), 'subjective norm' (how much the person feels social pressure to do it) and 'perceived behavioural-change' (whether or not the person feels in control of the action in question). Hence according to Fishbein and Ajzen (1975), the likelihood of intending to action a desired outcome is based on change in these three factors. Thus, CCy training can provide practitioners the opportunity to develop their intention by having increased awareness of factors influencing how one may present and respond to their difficulties which in turn may change 'attitudes', placing emphasis on achieving racial equity from an organisational perspective which may help with 'social norms', and finally providing ongoing encouragement and consultation within teams which can impact 'perceived behavioural-change'. This may in turn provide effective and appropriate care and skills, for example, effective communication and the ability to conduct cultural assessments (Walker et al., 2014).

Cultural competency within the NHS

Racial health disparities and inequalities have been noted for some time now (Chouhan & Nazroo, 2020). However, the global COVID-19 pandemic highlighted this further (Kamal, 2020). A global pandemic, effecting Black and Asian individuals more than White individuals in the UK alongside the murder of George Floyd in America, re-sparked discussions about racism and inequalities in the UK. Despite the apparent strong legal and policy framework (Department of Health, 2003), progress on this agenda appears limited. The challenges faced by minoritized and racialised populations when they encounter services in the UK are well documented and evidenced in previous research (Department of Health, 2005; Grey et al., 2013; NIME, 2003; Raleigh & Holmes, 2021; Singh et al., 2007). These papers highlight the ethnic inequalities of experiences and outcomes including concerns about patient safety, disproportionate number of admissions and detentions in psychiatric

hospitals, conflict with carers and staff, fear of services, a lack of available psychological therapies and inequalities in pharmacotherapy.

The UK holds an extensive list of legal frameworks and policies aimed at enhancing equity in healthcare often termed ‘equality’ in Britain, for patients regardless of their ethnic background within the NHS, including initiatives on policy directives (e.g., *the NHS Ethnic Health Unit*, 1994) and special initiatives (e.g., *Race for Health*, 2006, *Personal, Fair and Diverse*, 2010, and the *Equality Delivery System (EDS)*, 2011; 2013) (Randhawa, 2007; NHS England, 2013). These policies have been supported by a strong legal framework, from the 1965 Race Relations Act to the 2010 Equalities Act. The most recent framework has placed greater emphasis on the duty of the NHS to protect individuals from unfair treatment (NHS England, 2019).

Despite the commitment to equity in healthcare, evidence of racial disparities and health inequalities is widespread across a range of NHS settings (Salway et al., 2016). Much of these health inequalities within the NHS could be avoided with improved care and effective training (Salway et al., 2016). The apparent disconnect between national commitments and local provision of health services to patients from culturally-diverse populations raises questions about how central government policy translates into ClyC services.

Aims of the current review

To the author’s knowledge there are no reviews evaluating CC in the UK healthcare system, as such, the current review aims to systematically review the literature on CC in the UK healthcare system. Specifically, it will explore current conceptualisations of CC and aim to uncover what is currently being done in NHS services in regard to CC. This review also aims to evaluate any initiatives deployed to meet the needs of ethnically and culturally diverse populations.

Method

Literature Search

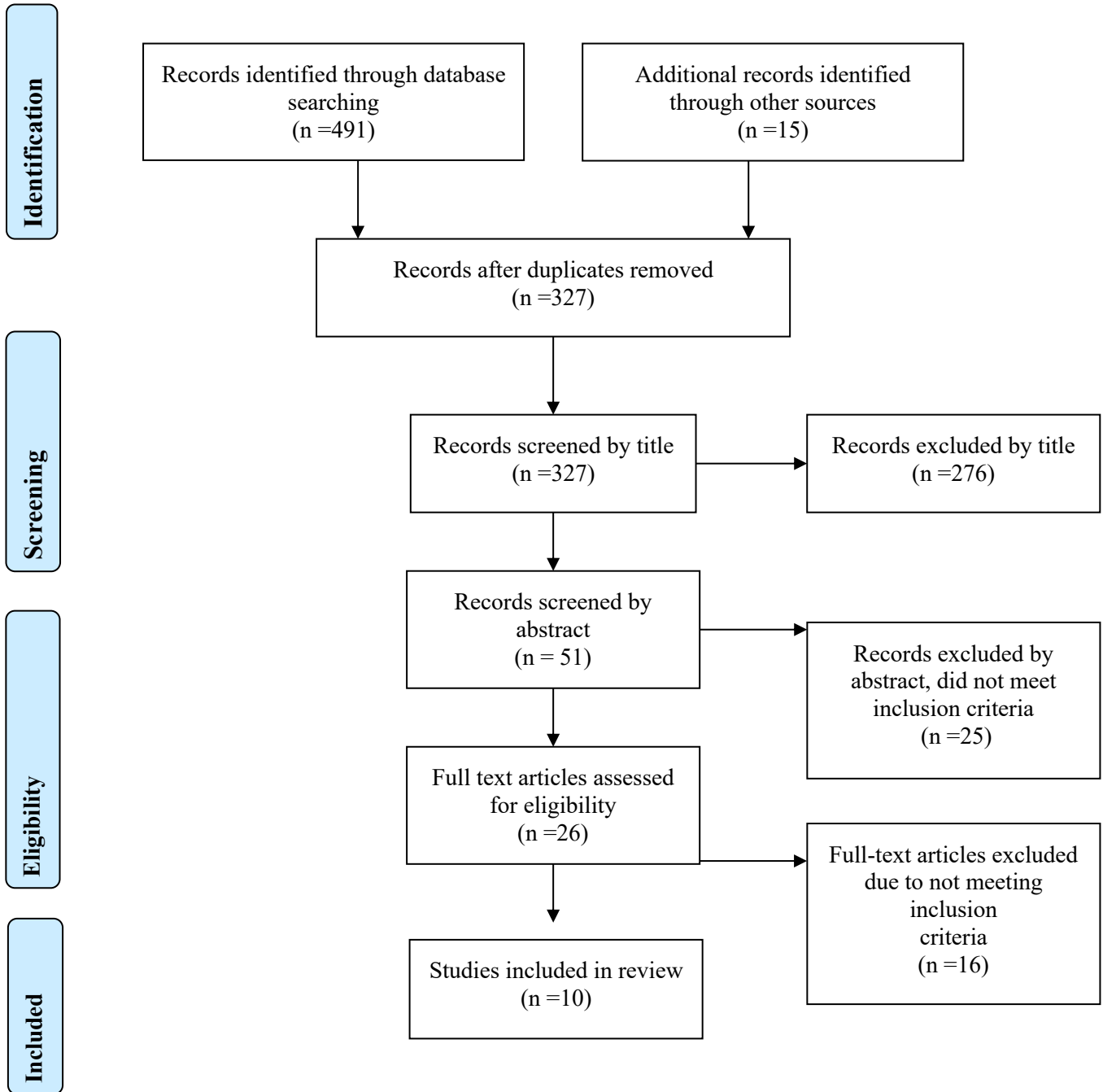
This review evaluated peer reviewed, published journal articles. A systematic literature search was conducted between 29/12/20 and 03/01/21. The database search included PubMed, PsycInfo, Medline, Web of Science and CINAHL and included papers that were published from their inception. Search terms included (cultural adaptation* OR cultural competenc* OR cultural identity OR cross-cultural issues OR cultural sensitivit* OR cultural competence assessment tool) AND (national health service OR NHS OR Mental health service* OR Physical health service* OR English health system OR UK healthcare) AND (BAME OR BME OR minority ethnic OR black OR Asian OR migration OR multicultural* OR super-diversity OR ethnic* OR People of colour) OR (race equalit* OR healthcare equity OR healthcare inequalities OR policy implementation OR ethnic-matching). Searches were broadened to include relevant terms in “abstract”, “title” and “keyword”. Papers were initially screened by title, and then abstract (Figure 1). Additional articles were searched for in the reference section of included papers as well as Google Scholar.

Eligibility criteria

The following inclusion criteria were used to meet the aims of the review:

1. Many of the reviews on CCy largely include US-based studies, therefore, only UK-based studies were included in this review.
2. Studies must have included evaluations of CC within the NHS context.
3. Papers were not excluded on the basis of research design, and so both quantitative and qualitative papers were included as long as they met all other criteria.
4. The study needed to be published in an English language, peer reviewed journal.

Figure 1: PRISMA selection process diagram



Quality assessment tools

As included studies for this review used both qualitative and quantitative designs (*See Table 1 for a summary of studies*), quality assessment was guided by the Mixed Methods Appraisal Tool (MMAT: Hong et al., 2018, see Appendix A). This is an effective and practical tool for systematic reviews that includes appraisals for varied study designs and mixed methods. The tool consists of two screening questions followed by five criteria for appraising study design. The MMAT appraisal summary (*Table 2*) displays the overall quality for the reviewed studies and the criteria not met where relevant. Overall, it was concluded that the studies included in this review were generally of good enough quality. However, given the lower ratings for Adamson et al. (2020), Bhui et al. (2015), Owiti et al. (2014) and Warnock-Parkes et al. (2010), the results of these studies were interpreted with caution in the synthesis.

Structure of this review

Due to the small number of studies included in this review and their mixed designs and approaches, discussions on papers and their quality will be integrated rather than consecutive. This approach enables the relative robustness of particular findings to be taken into account rather than individual papers. Results will be presented as themes. Themes were organically formed based on the main findings across all papers which were relevant to the aims of this review. Implications for future research and considerations for clinical practice are subsequently discussed.

Table 1. Summary of included papers

Authors, Date	Relevant aims/hypothesis to the review	Participants	Design, measures, analysis, evaluations of CC	Findings relevant to the review
1 Adamson et al. (2011)	- Examine staff perceptions of CC and the integration of CC principles in a mental healthcare organisation	Three samples to reflect staff across the organisation: corporate, operational, and direct care level - 6 corporate staff made up of department heads and directors - 14 operational staff made up of directors and senior nurse managers	Design: Mixed - methods Measures: Measures developed incorporating Seigel et al. (2000) conceptual framework with CC domains. Analysis: - Descriptive statistics	- Corporate and direct level staff agreed for the most part reporting moderate levels of CC, except for whose responsibility it was for CC in the organisation - Collectively, participants' narratives mainly focussed on individual practitioner responsibility for ClyC practice, with the organisational responsibility largely ignored - Accountability for race equality was not seen as a shared responsibility but was articulated as the domain of specialist staff, conveying a lack of ownership and the location of responsibility for any action to a small group for staff often in relatively junior positions.

- 73 direct care staff made up of: nurses, doctors, occupational therapists, psychologist, social therapists, and healthcare support workers.

- The framework approach (Miles and Huberman, 1994) was used to analyse semi-structured interviews

- Diversity in workforce tended to focus on lower graded posts than senior management posts

- Inconsistencies on ethnic data collection on participants and whether it is electronically updated

Sampling strategy:

Operational and corporate

level - purposive

Direct care – stratified

2	Bhui et al. (2015)	To evaluate a CCS ¹ designed to promote CCy	Sample: Staff working at a London based mental health trust	Design: Mixed – methods, feasibility pre-post study Measures:	Clinicians and SUs reported finding CCS process helpful reporting changes in communication, engagement, understanding, improved treatment plans and earlier discharge.
			Sampling strategy:		

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		Purposive		Qualitative: ethnography and participant observation Analysis: Quantitative: descriptive statistics Qualitative: Narrative synthesis	
3	Burchill & Pevalin (2014)	To evaluate CC in health visitors working with refugees	Sample: 30% of 42 available health visitors Sampling strategy: Purposive sampling	Design: Qualitative Measures: In-depth interviews Analysis: Interpretive thematic method using the	- Not all staff demonstrated CC - Staff described prejudiced beliefs and showed resentment towards SUs when level of need was high, and resources were limited. - Those who did adopted innovative ways of engaging and building relationships with SUs including helping SUs with filling out governmental paperwork, looking after babies

				Framework approach (Ritchie & Spencer, 1994)	whilst mothers went shopping and learning the SU's native language. - Governmental legislation was found to hinder CC skills at times.
4	Hussain et al. (2020)	To explore the views of staff adopting CCy initiatives measuring usefulness and practicalities of ethnic matching and the efficacy of diversity training	Sample: 20 participants including - CEO, progressing to middle-level management, and then to the lower levels of the Organizational hierarchy. This included eight executives, termed as Strategic Leaders (SL), six Middle Managers (MM) and six Frontline Staff (FS) members	Design: Qualitative Measures: Semi-structured interviews Analysis: Thematic analysis	- Challenges were found with workforce diversity initiatives - Although reported to be a key intervention to that could achieve the organisation's goals on diversity, ethnic matching was found to be difficult to achieve for several reasons e.g. ethnicity not being a fixed entity. - Diversity training was reported not to be successful in achieving a culture of equality and providing a quality service to ethnic minority SUs.

			Sampling strategy: Purposive sampling		- Initiatives were not always followed through in practice and a ‘one size fits all’ approach was adopted by the organisation
5	Owiti et al. (2014)	To evaluate the effectiveness of the cultural consultation service (CCS) model in facilitating the learning of cultural competence skills of clinicians within clinical encounters	Sample: 94 clinicians employed by four mainstream CMHT ² were expected and invited to take part in the intervention. Sampling strategy: purposive sampling	Design: Before and after study Measures: TACCT ³ Analysis: Qualitative: Interpretive content analysis Quantitative: Mann-Whitney U	- Clinicians reported developing a broader understanding of ‘culture’ and its influence on patients – learnt that culture is broader and more fluid and focusing on patient narratives is important. - Clinicians gained new knowledge and skills of managing the mismatch between patients and clinicians in their understanding of goals and expectations. - Clinicians learned a new method of assessment that incorporates techniques of ethnographic methodology of narrative collection including modelled ways of asking relevant questions.

					- Improvements in clinical cultural formulations presented to the referrer were seen. – socio cultural issues were incorporated into formulations. - Helps contextualise illness experience, and help seeking behaviour and leads to broader assessment lead to improvements in patient engagement in care.
6	Rathod et al. (2020)	To identify to what extent culturally competent and informed interactions are used by clinicians in England and how patients	Sample: 2805 participants, 2450 clinicians and 355 patients Sampling strategy: Purposive sampling	Design: Cross sectional study Measures: structured questionnaire designed by authors Analysis: categorical data analysis using Chi-square tests	- Discrepancies were found between clinician and patient responses. Clinicians and patients ‘most often’ agreed that a culturally specific assessment tool was ‘never’ used and agreement on levels of acculturation were ‘most of the time’ or ‘always considered’ - Disagreement in terms of whether setting of interaction was culturally appropriate or whether preferred language, migration history, barriers to accessing services, influence of religion, alternative pathways to care and cultural values relating to goals and social support networks were discussed.

experience these

interactions

– Clinicians felt these factors were taken into account ‘most of the time’ or always, whereas patients felt they were ‘rarely or never’ taken into account.

- Clinicians were more likely to feel they were being responsive to cultural needs if they had been working in their role for more than 10 years, had received specific training to work with different cultural groups and had a higher percentage of their practice involving ethnic minorities.

- Females clinicians more confident with their skills than males when taking culture into account.

- Overall – clinicians reported more competency than patients did leading to inconsistency between the two groups

7	Vydelingum (2005)	To explore nurses’ experiences of	Sample: 22 staff nurses and 18 care assistants Sampling strategy:	Design: Qualitative Measures: Unstructured	Staff demonstrated poor levels of Ccy. The following relevant themes emerged: Changes in services (we are doing our best)
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	caring for South Asian patients		interviews - Focus groups	False consciousness of equity (we treat everyone the same) Limited cultural knowledge (we don't understand them)	
			Analysis: Thematic analysis	Victim blaming (It's not our fault) Valuing the relatives (It's not our fault) Denial of racism (we don't have racism here)	
8	Warnock-Parkes et al. (2010)	To evaluate the effectiveness of South London forensic service in meeting the needs of ethnic minority SUs.	Sample: 47 staff representing all clinicians across MDT 41 male SU Sampling strategy: Purposive sampling	Design: Qualitative Measures: Semi-structured interviews using an adapted version of the Cultural Sensitivity Audit Tool for Mental Health Services (The Sainsbury Centre for Mental Health, 2001)	Staff outcomes: More than half felt BAME groups were overrepresented in the service – they attributed this to a misunderstanding of culture and the ways in which people express themselves Staff stated that culturally appropriate personal care products were available and believed that the food available fulfilled cultural and religious requirements - Less than half of the staff interviewed reported having a moderate to high level of knowledge of the Trust's anti-discriminatory policies.

Analysis: Thematic analysis

- 73% reported having some knowledge and skills but that these were not adequate and that they lacked confidence in their skills and knowledge.

- 49% of staff reported having not attended any training regarding ethnic and cultural issues

SU outcomes

80% of SU reported that they did not think the treatment they received was different from other people because of their ethnicity

71% of SU believed staff understood their cultural needs

71% reported having appropriate places to worship

49% stated that culturally appropriate personal care products were available

71% did not have a preference for ethnicity of keyworker

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9	Wilkinson & Randhawa (2012)	To explore how service providers viewed the progress made in delivering ClyC care to promote access within the diabetes care pathway	Sample: 14 service providers (public health manager, diabetes specialist nurse, diabetes and renal network manager, community health promotion worker, practice nurses, general practitioner, link worker and community diabetes educator) from three study sites: Leicester, Luton and London	Design: Qualitative Measures: Semi-structured interview Analysis: Thematic analysis	<ul style="list-style-type: none"> - Overall poor levels of CC were found among staff - Staff reported trying to adopt a ‘one size fits all’ approach by encouraging Eurocentric ideas of self-management which at times were incongruent with SU ideas on management. - Examples of adaptations were reported e.g. providing education in the community - Differences in patient-clinician expectations were reported, barriers to overcoming challenges included time and resources
Sampling strategy: Purposive sampling					
10	Zeh et al. (2018)	To look specifically at the	Sample: 34 General practices in Coventry, Surveys were	Design: Cross sectional study	- Most frequent barrier to delivering ClyC diabetes services was language, knowledge of nutritional habits, cultural

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workforce	completed either by practice	Measures: Structured	differences between minority patients and health care
cultural	managers, GPs or a practice	survey using CCAT ⁴ .	providers.
competence	nurse.	Areas focused on	- Nurse patient appointments held in the clients' own
within GP		linguistic need,	language were reported as indicators of CC.
practices in a city	Sampling strategy:	cultural awareness,	- 6 of 32 practices that had a minority diabetes lead nurse
where one in	Purposive sampling	cultural knowledge,	and/or other minority staffing delivered highly CC diabetes
three people with		service providers	services, whereas services with few or no minority staff
diabetes is an		being ClyC and	attained low scores of CCAT scores
ethnic minority		culturally sensitive	- 32% of staff spoke a language relevant to the practices'
		Analysis: Descriptive	minority population.
		statistics and thematic	
		constant comparative	
		analysis	

¹CCS – Cultural Consultation Service. ²CMHT – Community Mental Health Team. ³TACCT - Tool for Assessing Cultural Competence Training (TACCT) – a self-evaluation tool for cultural competence. ⁴CCAT – Culturally-Competent Assessment Tool (Zeh et al., 2012)

Integrative review

Overview of studies

All studies evaluated CCy within the UK Health services. Of the ten studies, one used a single “before and after” study design (Owiti et al., 2014), two used a cross sectional design (Rathod et al., 2020; Zeh et al., 2018), five used a qualitative study design (Burchill & Pevalin, 2014; Hussain et al., 2020; Vydelingum, 2005; Warnock-Parkes et al., 2010; Wilkinson & Randhawa, 2012), and two used a mixed-methods design (Adamson et al., 2011; Bhui et al., 2015). The studies largely focussed on evaluating levels of CC across different NHS services across England (Appendix B). All studies collected data from adult mental health or physical health settings.

Table 2. MMAT (2018) summary table of appraisal

<i>Study</i>	<i>Design</i>	<i>MMAT score/criteria met</i>	<i>MMAT criteria not met</i>
Adamson et al. (2011)	Mixed methods	Quant: 4/5 Qual:4/5 MM:3/5	Low response rate Insufficient quotes provided, unclear if results are adequately derived from data Lack of rationale for a mixed methods study. Not all quality criteria satisfied for qualitative and quantitative components
Bhui et al. (2015)	Mixed methods	Quant: 3/5 Qual: 4/5 MM:3/5	Incomplete outcome data. Confounders not accounted for. Insufficient quotes provided, unclear if results are adequately derived from data Lack of rationale for a mixed methods study. Not all quality criteria satisfied for qualitative and quantitative components
Owiti et al. (2014)	Quantitative	3/5	Incomplete outcome data, low response rate. Confounds not accounted for in design or analysis.

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Rathod et al. (2020)	Quantitative	4/5	Non-response bias cannot be ruled out. Disproportionately higher response rate from clinicians vs SUs. No information about those who did not take part.
Zeh et al. (2018)	Quantitative	5/5	n/a
Burchill & Pevalin (2014)	Qualitative	5/5	n/a
Hussain et al. (2020)	Qualitative	5/5	n/a
Vydelingum (2005)	Qualitative	5/5	n/a
Warnock-Parkes et al. (2010)	Qualitative	3/5	Insufficient quotes provided, difficult to determine if findings adequately derived from the data. Insufficient information provided to ascertain coherence between stages of research.
Wilkinson & Randhawa (2012)	Qualitative	5/5	n/a

Conceptualisations of CC

Conceptualisations of CC differed across the papers. Three studies (Warnock-Parkes et al, 2010; Vydelingum, 2005; Zeh et al, 2018) emphasised cultural sensitivity, responding to cultural needs and linguistics as being key indicators of CC. In addition to these factors, three papers (Burchill & Pevalin, 2014, Rathod et al, 2020; Wilkinson & Randhawa, 2012) also emphasised the importance of social context and illness perceptions as important factors when considering CC. One paper (Adamson et al, 2020) emphasised organisations' need to be responsive to the 'cultural needs' of the populations in which they serve. Although the authors did not expand on this further, the paper adapted a CC model to evaluate CC in the organisation which emphasised social and cultural factors. Three papers (Bhui et al, 2015; Hussain et al, 2020; Owiti et al, 2014) took a more critical view of 'culture' arguing that culture went beyond ethnic and minority stereotyping. Both authors rejected definitions of CC which included fixed and generalised ideas of specific cultures.

Approaches to exploring CC

Evaluations of CC varied across the studies. Of the ten studies, two (Adamson et al, 2011; Hussain et al, 2020) adopted an entire organisational approach to evaluating CC across three different levels within an organisation. However, labels of the three levels differed, with one study (Adamson et al, 2011) describing the three levels as corporate, operational and direct care, and the other study (Hussain et al, 2020) describing the levels as strategic leaders, middle managers, and frontline staff. Five studies (Burchill & Pevalin, 2014; Owiti et al, 2014; Vydelingum, 2005; Wilkinson & Randhawa 2012; Zeh et al, 2018) evaluated CC in frontline staff. Of these studies, one study (Burchill & Pevalin, 2014) evaluated CC skills in health visitors working with refugees in NHS primary care services in a Central London Borough, two (Wilkinson & Randhawa, 2012; Zeh et al, 2018) evaluated CC in clinicians

working in diabetes services across England who worked largely with South Asian SUs, one evaluated CC in nurses working with South Asian clients at a general hospital, and another (Owiti et al, 2014) evaluated the impact of a new cultural consultation service (CCS) with staff across mental health services within an NHS Trust. The remaining three studies evaluated CC (Bhui et al., 2015; Rathod et al., 2020; Warnock-Parkes et al., 2010) from a service perspective seeking feedback from both clinicians and SUs.

Of the studies reviewed, one (Burchill & Pevalin, 2014), used a model to assess levels of CC skills across an organisation or within staff, and two (Rathod et al., 2020, Zeh et al., 2018) created their own measures based on previous research. Three studies (Hussain et al, 2020, Vydelingum, 2005, Wilkinson & Randhawa, 2012) created interview guides to address specific aims related to their research. Two studies (Bhui et al., 2015, Owiti et al, 2014) adapted both a model and measure of CC and one study (Adamson et al, 2011) used a CCy model to create their own assessment tool. The final study (Hussain et al, 2020) created an interview guide to assess CCy, however details of what the questions entailed were not provided.

Despite the variations in approaches to measuring and evaluating CC, there were overlaps across the studies. For example, though Zeh et al. (2018) and Rathod et al. (2020) adopted different approaches to measuring CC, measures utilised in the studies focused on language skills, an awareness of cultural norms and practices, awareness of context and delivery (cultural sensitivity) and therapeutic alliance. Similarly, although Burchill and Pevalin (2014) utilised Quickfall's (2004) model of assessing CC. The model includes five domains with a similar focus to the measures described above (i.e., institutional regard, cultural awareness, cultural sensitivity, cultural knowledge, and CC). Interview transcripts were analysed against each of the domains.

Though Adamson et al (2011) utilised a Siegal's (2000) CCy framework, the areas of focus differed from other measures or models of CC. Adamson et al (2011) adopted an organizational approach by focussing on needs assessment, information exchange, services, human resources, policies/procedures, and CCy outcomes. Both Owiti et al (2014) and Bhui et al. (2015) focussed on an organisational approach with senior and direct care level staff. Both studies evaluated outcomes for a CCS which assessed CC in staff. Bhui et al. (2015) additionally assessed SU outcomes. Though the original Tool for Assessing Cultural Competence Training (TACCT) (Lie, 2006) focuses on six domains, the adapted version focusses on the last domain which assesses Cultural Clinical Skills. Authors did not provide any further details on what this entails. Warnock-Parkes and colleagues (Warnock-Parkes et al, 2010) utilised a pre-existing measure, The Cultural Sensitivity Audit Tool for Mental Health Services (The Sainsbury Centre for Mental Health, 2001) to evaluate CC in staff and SU. The measure placed emphasis on the experiences of people using and working in services, consisting of two interview schedules: staff and SU interview schedules. The staff schedule included six domains: demographics, communication, availability of staff to work with clients, knowledge and views of cultural and ethnic issues, cultural training, and cultural appropriateness of the setting. The SU schedule consisted of seven domains: demographics, accessibility of services, language and interpreters, general service issues, availability of appropriate staff, availability of ethnic specific services, and SUs' views on the cultural appropriateness of mental health services.

Wilkinson and Randhawa (2012), Hussain and colleagues (Hussain et al, 2020) and Vydellingu, (2005) used qualitative interviews to explore CC. The authors did not provide details on the questions asked.

Results

Results from the papers can be summarised in five broad categories: Workforce diversity, diversity training, clinician knowledge, sensitivity and skills, adaptations and SU perspectives. These will be discussed in turn below.

Diversity training

Almost all participants across the studies reported that current levels of diversity training were inadequate. The exception to this was teams and organisation who provided specialist training on working with diverse cultural populations (Burchill & Pevalin, 2014; Rathod et al, 2020). Participants across the studies received mandatory Equality and Diversity training by their employer. These largely focused on anti-discriminatory practice while working with diversity across the board with no content on ‘culture’. On the whole, this was found to be tokenistic and unhelpful within their clinical practice. In one study (Adamson et al, 2011), the host Trust had introduced a Race Equality Cultural Competence (RECC) programme which was compulsory for all clinical staff, however the training only included issues of race awareness and communication rather than addressing clinical practice. Furthermore, the training was not mandatory for senior management and the board of directors. Only 35% of clinical staff interviewed reported attending the CCy training (Adamson et al, 2011). Similarly, only 51% of clinicians in a separate study (Warnock-Parkes, 2010) reported attending such cultural diversity training. In one study (Zeh et al, 2018), participants reported needing further funding to increase CC skills in staff and to improve services for their minority patients.

Clinician knowledge, sensitivity and skills

Reported levels of clinician knowledge and skills varied across the studies. A lack of knowledge and sensitivity was found to impact quality of care in some studies (Burchill &

Pevalin, 2014; Zeh et al, 2018; Vydelingum, 2005), while increased knowledge of cultural norms and sensitivity were reported to improve relationships, engagement and quality of care (Burchill & Pevalin, 2014). Lack of knowledge and sensitivity were demonstrated by increased clinician prejudice and bias, othering, victim-blaming (Vydelingum, 2004), and by ‘treating all patients the same’ (Burchill & Pevalin, 2014; Zeh et al, 2018; Wilkinson & Randhawa, 2012; Vydelingum, 2004). Lack of knowledge was also demonstrated by a lack of awareness of different populations within the local area and limited documentation regarding patient ethnicity and faith (Adamson et al, 2011; Zeh et al, 2018), lack of awareness of culturally appropriate environments (Burchill and Pevalin, 2014; Rathod et al, 2020; Vydelingum, 2004), and lack of awareness of illness perception and management (Wilkinson & Randhawa, 2012). Some studies found that quality of care was often compromised due to organisation, social and contextual difficulties such as lack of use of interpreters (Zeh et al, 2018), policies which restricted rights and access to care, housing, immigration, welfare and benefits (Burchill & Pevalin, 2014), and lack of resources and flexibility in clinician diaries for longer appointments (Wilkinson & Randhawa, 2012).

Conflicting views on responsibility for providing ClyC services were found. For example, disagreements between direct care staff and senior management were reported in one paper (Adamson et al, 2011). Senior management described that it was the responsibility of direct staff to ensure their practice is ClyC, while direct staff reported that it was the responsibility of specialist cultural and diversity leaders, implying a lack of ownership and the assignment of responsibility to a small group of junior employees (Adamson et al, 2011).

Two studies (Bhui et al, 2015; Owiti et al, 2014) introduced a CCS model into an organisation. With this, the authors saw a significant improvement in how clinicians rated their CC from baseline to follow-up. CCS was reported to improve clinician attitudes, knowledge and skills. Furthermore, clinicians reported a range of key learning outcomes

including, a broader understanding of culture and CC, development of skills in managing complex cases/presentations integrating social contexts of illness experience and the impact of factors such as identity, psychosocial environment, migration and government policies, and improved assessment skills and developing cultural formulations. Such skills helped to reduce miscommunication between patients and clinicians, increase diagnostic clarification, patient and family engagement, and autonomy and choice (Bhui et al, 2015).

Adaptations

Examples of innovative practice and adaptations were also reported in studies. In one study (Burchill & Pevalin, 2014), some health visitors spoke of strategies employed to increase engagement and demonstrated CC, for instance, previous experience working abroad, learning patient's native language and practicing with them, providing baby-sitting and providing assistance filling out government forms. Another study offered specific self-management training for 'minority patients' (Zeh et al, 2018).

Use of adaptations were perceived by clinicians to be a good indicator of being ClyC. For example, in one study, (Zeh et al, 2018), participants felt the biggest indicator of meeting needs was to offer appointments in the patient's own language. All but one GP practice surveyed in this study were reported to use interpreters or staff who could speak the same language. In one study, changes to practice and increased knowledge led to changes in treatment plan, improved engagement, increased medication compliance and earlier discharge (Bhui et al, 2015). However, studies also found that a common barrier in providing ClyC services was due to a lack of resource within teams and services to enable clinicians to implement recommendations (Bhui et al, 2015, Wilkinson & Randhawa, 2012).

While studies that implemented adaptations reported them to be useful, one study found a lack of adaptation in practice. In order to standardise practice and empower clients, clinicians were reported to keep their clinical practice the same regardless of the client's

background. While this was done with the intention to increase empowerment and self-management, it at times led to a gap between patient and provider expectation and disengagement (Wilkinson & Randhawa, 2012).

Workforce diversity

Targeted recruitment and ethnic matching were initiatives adopted by some organisations to increase workforce CC as it is believed that a diverse workforce is better able to meet the needs of minority patients. Two papers (Adamson et al, 2011; Hussain et al, 2020) found that the organisation had a targeted recruitment campaign to attract greater numbers of minority staff. However, these posts were for lower graded posts rather than senior management posts, thus re-confirming that CC is often viewed as the responsibility of direct care staff at an individual level rather than at an organisational level.

One study found that services with higher levels of CC were those with higher numbers of staff from minority backgrounds. Existence amongst staff of cultural and linguistic skills was seen to bring CCy to services (Hussain et al, 2020; Zeh et al, 2018). However, another study (Hussain et al, 2020) concluded that workforce diversity initiatives were ineffective and could bring challenges. This was because ethnic minority SUs often have multi-layered identity patterns based on their individual experiences. Furthermore, it was found that filling junior posts became challenging as such roles were not always encouraged in some cultures. In addition to this, a lack of focus and priority to achieve workforce diversity was found in both studies. For example, in one study (Hussain et al, 2020), the authors found that the organisation had only included one question to assess cultural capability in recruiting to the post, despite the role including working with cultural diversity as a primary component.

SU perspectives

Three studies (Bhui et al., 2015; Rathod et al, 2020; Wilkinson & Randhawa, 2012) focused on SU perspectives in addition to organisational and clinician perspectives. Two studies (Rathod et al, 2020; Warnock-Parkes et al, 2010) found some disparities between SUs and clinician perspectives. Clinicians often reported high levels of CC, reporting they ‘most often’ used a culturally specific assessment, whereas patients reported this ‘never’ occurred. Furthermore, there were disagreements in whether the environment was culturally appropriate and whether barriers to accessing services, migration history, preferred language, influence of faith, cultural values relating to goals were discussed with clinicians stating this occurred ‘always’ or ‘most of the time’ and patients reporting ‘rarely’ or ‘never’. Finally, clinicians reported that they always considered cultural importance and attended to cultural needs, whereas most patients (57%) reported that they had not been asked about any cultural explorations of distress (Rathod et al., 2020). Interestingly, in one paper (Warnock-Parkes et al, 2010), clinicians reported a lack of confidence in their cultural skills and knowledge whereas SUs reported their needs had mostly been met other than receiving culturally appropriate personal care items. One study (Bhui et al., 2015) collected feedback on a new CCS, and in this SUs reported that speaking to the cultural consultant was helpful as they felt listened to and not judged. Furthermore, the process helped SUs to recognise what was going on for them in more detail.

Overall levels of CC

Overall, the studies demonstrated mixed levels of CC with variations in how CC was conceptualised and operationalised. For the most part, conceptualisations of CC were limited to cultural diversity and an understanding of the patient’s ethnic culture and the ability to communicate with patients in their native language. High levels of CC were attributed to having increased workforce diversity, use of interpreters and having a cultural understanding of illness perception and social context. Of the ten studies reviewed, less than half (Adamson

et al, 2011; Bhui et al, 2015, Burchill & Pevalin, 2014; Owiti et al, 2014) reported receiving specialist CC training, despite all papers focusing on services with a large population of minority SUs.

Discussion

Methodological limitations

Studies included in this review utilised a range of designs to evaluate CC in UK healthcare settings. All the studies included in this review either adapted or created a new measure of CC, all of which remained unvalidated. However, authors where possible attempted to account for this by running a pilot study, or preliminarily tested measures before rolling them out more widely. Another limitation among the quantitative studies was that response rates largely varied, with most studies having a low response rate. Furthermore, authors did not provide any information on those who did not participate; hence it could be that only those who potentially felt more confident in their levels of CC responded. All the studies utilised self-report of some form and so it is difficult to rule out potential social desirability effects and bias, particularly in studies where a single clinician filled out measures on behalf on an entire service. It could be that their perception of what was happening did not match the reality of services offered to culturally-diverse populations. At times topic guides were not included so it was unknown what the participants were asked. Some studies did not record participant ethnicity. This was a significant omission given that perceived levels of CC were being evaluated. Recording of participant ethnicity could have provided further insights into ideas of whether clinician characteristics aid CC. One study evaluated explored if SUs language needs were met, yet unhelpfully they only interviewed fluent English-speaking participants (Warnock-Parkes et al, 2010). Finally, as many of the studies were case studies, the findings cannot be generalised more widely. All ten studies demonstrated a lack of robust methods in measuring CCy in services when taken together.

The average methodological quality of reviewed studies is evidenced by problematic designs, sampling bias and unvalidated outcome measures, prevented any conclusive conclusions about CC in UK healthcare settings.

Conceptualisations of CC

This review found problems with conceptualisations of CC. Firstly, not all studies directly asked participants about conceptualisations of CC, and conflicting understandings were reported across the studies. While some adopted a broader definition of CC, researchers and clinicians largely understood CC to be synonymous with an understanding of race, culture and language. This reflected findings of a recent review which explored conceptualisations of CC in the wider literature mirroring wider misunderstandings of CC (Henderson et al., 2018). This review found that in some studies, authors conceptions of CC influenced how CC was measured. Consequently, if authors understood CC in the limited sense of being culturally sensitive and having an awareness of linguistics, then evaluations focused in on this narrow notion. Therefore, it was difficult to assess if limited conceptualisations were due to how evaluations were set up by researchers.

Inconsistent definitions of CC were also found in international reviews (Alizadeh & Chavan, 2015; Jongen et al., 2018; Renzaho et al., 2013; Troung et al., 2014). The lack of consensus on CC is problematic as it has a direct impact on the initiatives adopted by organisations. The absence of consistent definitions leads to major gaps in knowledge and various divergent narratives on what constitutes inequality, solutions and uptake, and nature of training initiatives. This poses a significant risk, as when or if conceptualisations of CC are limited, the initiatives adopted can be ineffective in reducing health inequality or worse invertedly continue to perpetuate them. CC requires a more defined definition and set of criteria that are related to particular clinical and non-clinical competencies (Bhui et al., 2007).

Operationalisations of CC

Different approaches to assessing and evaluating levels of CC were found in this review, with only two studies adopting an entire organisation approach. Discrepancies in accountability for race and equality among senior level and direct care staff were found in this review. For example, the responsibility was largely reported to belong to either direct care staff or to specialist staff whose role included advocating for race and equality. Interestingly, the responsibility was found to lie with staff who were often in junior positions. Previously, CC has largely been seen to be the responsibility of individual staff, rather than the responsibility of the entire organisation (Garneau & Pepin, 2015). While such approaches may be easier to measure, this turns the attention to individual practice rather than how organisations are tackling and managing health inequalities and meeting the needs of culturally-diverse populations (Sue, 2001). This has been found to be common practice in regulatory and educational health organisations where understandings of CC have been framed towards individual practice rather than organisational/systemic process, and on gaining cultural knowledge rather than reflective self-assessment of social structures, power, privilege and bias. This approach can potentially be harmful and undermine progress in reducing racial health inequalities (Curtis et al., 2020).

However, it is recognised that these studies highlighted the organisational flaws in approaches to CC. For example, highlighting issues with training offered to increase levels of CC in staff. Clinicians were largely offered Equality and Diversity training, with an expectation that it would enhance CC in staff. While reducing racial health inequalities is spoken of as an important agenda in wider legislation and policies, this review highlighted that in practice, efforts are largely insufficient. As it is, CC is largely understood as ‘having an awareness of the patient’s culture and language’, so therefore attending a one-day training on ‘culture’ and the use of an interpreter is a simple solution to meet the needs of that patient.

CC training was designed to enhance clinician self-awareness of attitudes towards patients, increase knowledge about populations served (e.g., social context, health behaviours, medication response, cultural beliefs and practices, attitudes towards healthcare system and healthcare seeking behaviours), and to improve communication skills (Branch & Fraser, 2000). It seemed little surprise that a lack of knowledge was found in this review given the limited training offered to clinicians across the studies. Williamson and Harrison (2010) found that CCy training strategies were mostly based on essentialist conceptions of culture (overlooking social structures) and based on the assumption that understanding one's own culture brings tolerance. However, evidence suggests that an awareness of cultural difference is incapable of bringing about transformation in therapeutic relationships (Jenks, 2011). Furthermore, it does not eliminate ethnic, racial and cultural discrimination, rather has been found to lead to strengthening Eurocentric approaches to care (Williamson & Harris, 2010). Contrary to this, this review did find that poor knowledge and lack of sensitivity were found to negatively impact quality of care in some studies, whereas increased knowledge of cultural norms and sensitivity were reported to improve relationships, engagement, and quality of care in other studies.

In some studies, a lack of awareness of power imbalances and prejudiced attitudes were found towards patients from ethnic minority backgrounds. This sat within the wider context of prejudiced beliefs held towards ethnic minorities in Britain (Shankley & Rhodes, 2020). It is important to recognise the broader social structures and economic inequalities which translate into profoundly poorer outcomes for patients from minority backgrounds. It is furthermore important to consider how policy and practice typically translate into a socially influenced or constructed phenomena, and ethnicity and health, into essentialised constructs that are typically reduced to biology (Garneau & Pepin, 2014). By examining the way healthcare is provided and the outcomes of that care to culturally-diverse populations, it is

possible to begin to explore how an institution that is central to lives serves to address, or amplify, broader racialised social structures (Chouhan & Nazroo, 2020).

Limited conceptualisations of CC were demonstrated through recruitment strategies deployed by some organisations (e.g., ethnic matching), as it is believed that a diverse workforce is better able to meet the needs of patients. However, this review found problems with this, firstly, that roles were largely allocated to employees at junior level. This reflects national data which highlights ethnic minorities to be over-represented in the NHS workforce, but significantly under-represented as NHS Trust board members across England (NHS England, 2020). Secondly, ‘ethnic matching’ proved to be challenging as organisations struggled to fill posts. The participants reported that this was due some roles not being encouraged in some cultures. Furthermore, while diverse workforces can be beneficial for a number of reasons, ethnic matching can prove to be challenging given intersectionality and diversities intra-culturally.

This review found a number of barriers in providing ClyC care to patients from culturally diverse backgrounds. For example, organisational challenges such as a lack of resources, time and funding were often reported to hinder ClyC delivery of services. Efforts furthermore held a false sense of equity, for example, reports of ‘treating all clients the same’ and standardising practice were common in this review. These findings further highlighted a lack of knowledge around how health inequalities come about and what can help to reduce these and increase good health, care and engagement.

Despite the above barriers, this review found promising evidence of an effective CCS as well, which improved the knowledge of health professionals, diverse-client engagement and outcomes for clients. Furthermore, this review found innovative initiatives adopted by staff in some organisations to help reduce inequalities and improve engagement.

Interestingly, initiatives reported included cultural awareness as well as improving an

understanding of the social context of the client and barriers to engagement, for example, helping refugee mothers in filling out governmental forms and providing baby-sitting for mothers while they did their shopping (Burchill & Pevalin. 2014). This is a good example of understanding difficulties within the context of social structures and previous experiences, and how these might be communicated based on cultural understandings. This approach differs to the one largely seen in practice of associating distress and presentations with a particular culture. However, this review found that such practices were not commonplace. Adaptations were perceived to be a good indicator of CC, however this was largely thought of in relation to meeting linguistic need and the use of interpreters.

Time to move away from CC...

The COVID-19 global pandemic and the murder of George Floyd in America stimulated immediate and long overdue global conversation about race inequality and racial health inequalities. Action to decolonise curriculums on health and psychology courses and improve health equality in NHS services were initiated. While racial health inequality has been long spoken about, this review highlighted that this often gets forgotten about in practice behind resourcing deficits, chaotic running of services, and bureaucracy. These initiatives require recognition of how historical powers of racism and empire continue to construct power hierarchies in medicine and psychology programmes, including dismantling of power imbalances between clinicians and patients (Bhambra et al., 2018). This review highlighted a lack of knowledge and awareness of issues facing patient populations and at times, the prejudiced beliefs held by clinicians. Biased attitudes whether conveyed in an explicit or implicit way, disadvantage and disempower patients, negatively impact levels of trust in the clinician-patient relationship and long-term health outcomes, and relocate health problems in race (Baug et al., 2020). It is believed that CC addresses these problems and assists in the reduction of inequalities (Bhui et al., 2007).

Although this review has demonstrated examples of innovative adaptations, and shown promising results for a CCS, it has largely found problems with conceptualisations and operationalisation of CC. The core assumption of CC is that with enough knowledge, preparation, and practise, it is possible to acquire the skills needed to overcome cross-cultural barriers in clinical settings (Davis, 2020). This review has found that clinicians had received limited training which was often limited to half a day's Equality and Diversity e-learning course. Similarly, examples of CC training in educational settings were often comprised of fictitious vignettes inspired by minority stereotypes. In these students were encouraged to explore 'appropriate' considerations and responses which were also often derived from stereotyped ideas (Razai, 2016). This training was seemingly often experienced as a tick box exercise and given limited time in comparison to other areas of employee competence training.

Effectively being able to meet the needs of ethnic minority patients requires moving beyond the training room and engaging in a continuous reflexive process in clinical settings. Kolb (1984, p. 38) defined learning as

“The process whereby knowledge is created through the transformation of experience.”

This suggests learning to be a continual holistic process and not a product achieved following a single training session. Kolb (1984) argued that learning is a continual process of doing, reflecting and adapting. As such, initiatives to reduce racial health inequality should reflect this. Curtis et al. (2020) model of 'cultural safety' places emphasis on continuous self-reflection and engagement on the perspective of patients, which in theory produces awareness of the clinician's own assumptions, biases and dispositions. This model brings to awareness how systemic barriers to healthcare access and institutional racism contribute to a disparate health burden on ethnic minorities (Curtis et al., 2020). Currently, CCy initiatives fail to

address systemic, structural issues of race and power and their impact on ethnic minorities. Critical approaches to ‘culture’ should be adopted in training sessions, recognising the term as a dynamic construct as opposed to being synonymous with race or ethnicity. Together an awareness of systemic and structural issues of race and power can obliterate assumptions of culture being seen as the locus of pathology, and the place where all complexity lies (Hudson, 2017). This will enable clinicians to respond to cultural difference without engaging in narratives that homogenise, exoticize, or marginalise the patient or perpetuate and engage in a process of ‘othering’, which is a risk or consequence of current CC trainings (Harrison & Turner, 2011; Herring & Spangaro, 2013).

Limitations of this review

To the author’s knowledge, this is the first review exploring CC in UK healthcare settings. This review has been able to highlight gaps in the literature and make recommendations for future research below. The papers reviewed in this review were identified using a systematic search strategy which incorporated electronic databases, search engines and reference lists of reviewed papers. It is highly likely that the studies in this review are representative of the peer-reviewed published literature in the UK. However, being a non-exhaustive search strategy, it is possible that some relevant papers were not found. Furthermore, this review included studies with differing aims and approaches, however given the scarcity of UK based studies on CC and the lack of UK based reviews, it meant that a broader scope was ultimately useful in understanding the wider literature. It is acknowledged that many of the papers reviewed in this study were published over a decade ago and with the introduction of new policies and initiatives, this review may not reflect current practice.

Clinical implications

The results of this study cannot provide sufficient evidence for what constitutes as good practice. This review reflects the previous literature which highlights discrepancies in both conceptualisations and operations of CC (Alizadeh & Chavan, 2016; Hernandez et al., 2015). This review highlights promising evidence for a new CCS which included an understanding of social context and individualised narrative assessments. Furthermore, this review highlights the importance of adequate training, self-reflection and education in social context and narrative assessments in providing effective care, improved relationships and patient outcomes. Recommendations for evaluating current approaches to reducing racial health inequalities within organisations are recommended. Literature on CC suggests a core component of CC is self-reflection, however, this review found that this at times was missing in practice. Critical consciousness of one's own biases, an awareness of socio-historical context and power imbalances are crucial in beginning to reduce health inequalities. Part of this process includes attending to and critiquing power structures, challenging one's own culture and cultural systems over the prioritisation of becoming 'competent' in the cultures of the other (Curtis et al., 2020). Furthermore, it is important that initiatives and activities are clearly linked to achieving health equity and are monitored on a regular basis as this review found that CC initiatives were not monitored in practice. This can result in losing sight of the goal.

Research implications

Global literature on CC has indicated mixed findings, while some previous reviews have provided evidence for the efficacy of CC initiatives, this review did not find the same. However, it is noted that research on CC is still in its infancy in the UK, given recent discussions around racism and inequality, it would be a good time to push forward with research into how racial health disparities can be reduced and monitored. None of the

included studies measured the effect of CC interventions on healthcare disparities. Most of the studies reviewed measured levels of CC in staff via self-report. This is problematic given the vast research on bias in self-report data with ample research indicating the over-reporting of skills (Yu, 2020). This is even more problematic in relation to over-reporting of CCy skills which indicates a service to be ClyC on measures but inadequate in practice. This can have severely negative outcomes for patients and further increase inequalities. More robust measures of assessing CC, which use a variety of methods are needed. Hence it may be helpful for future research to measure the impact of CC in reducing health inequalities and improving health outcomes for culturally diverse populations. This review found that the voice of SUs was largely missing in papers exploring CC. Given that CC directly impacts care, it is important for future research to include the voice of SUs. Promising evidence was found for CCS, given that the paper reviewed in this study was a feasibility “before and after” study, RCTs evaluating CCS would be helpful. Overall, a lack of monitoring of CC was noted across the studies, perhaps this is related to limited measures on CC.

Conclusion

The paucity of high-quality research on CC in UK healthcare is apparent. This review highlighted problems in conceptualisations and operationalisations of CC. While literature has advanced away from limited conceptualisations of ‘culture’ and CC, this review demonstrates that in practice, views of cultures as static and/or stable continue to exist. CC still appears to be synonymous with race, ethnicity and language. A shift is required towards engaging in a process of ‘cultural safety’ in organisations. This involves a critique of power imbalances and continuous critical self-reflection rather than current static notions of having achieved CC following a one-day training course. Having an awareness of social context, historical influences, and focus on individual narratives, one engages less in an ‘othering narrative’ which perpetuates prejudice. This could help organisations move towards reducing

racial health inequalities and meeting the needs of culturally-diverse populations. More robust research is needed on how best to train and monitor for culture which embraces 'cultural safety' within healthcare organisations. Furthermore, it was evident in the studies reviewed that the voice of patients is missing. Therefore, future research which includes the voice of patients is needed.

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SECTION B

**‘With Hardship Comes Ease’: Black and Asian Individuals’ Experiences of
Functional Neurological Disorder**

Word Count: 8,084 (99)

For the submission to Culture and Brain

ABSTRACT

Functional Neurological Disorder (FND) is an umbrella term used to explain a wide range of physical symptoms that resemble disorders of the nervous system without organic cause and often no physical health explanation is found (Reuber et al., 2007). Research indicates that individuals and their families find the diagnosis of FND difficult to understand and the transition from a physical health setting to mental health services challenging (Kozłowska et al., 2018). There are currently no studies into the experiences of Black and Asian individuals' experiencing symptoms of FND. This study explored whether family, faith or culture play a role in the experience of FND in Black and Asian cultural and faith-based groups. Semi-structured interviews were conducted with seven individuals. Interviews were analysed using Interpretive Phenomenological Analysis. The results indicate that individuals largely understood their symptoms from a Eurocentric medical lens, but that the diagnosis was difficult to come to terms with. Cultural influences such as help-seeking behaviours, symptom and suffering perceptions, upbringing and language were found to play a part in how one experiences FND. Stigma and faith were found to play a significant role in individual's experiences. Stigma in perceptions of symptoms from family and friends and health care professionals (HCPs) was found to have a negative impact on individuals' own perceptions of their difficulties. Faith was found to play a significant role, offering individuals comfort and support. This has clinical implications for the way individuals engage with services and HCPs.

Keywords: Functional Neurological Disorder, Faith, Culture, Black, Asian

Introduction

Due to continuous global migration, the population of the United Kingdom (UK) is culturally and ethnically super-diverse, with reports of over 200 ethnic groups in the UK over a decade ago (Vertovec, 2007). The current demographic profile is likely to be much more diverse. Along with this, 68% of respondents from the 2011 census reported identifying as belonging to a religious group (Gov UK, 2018). Growing super-diversity brings a greater diversity in experiences, perceptions and beliefs about health and psychological distress (Sheik & Furnham, 2000). This has reportedly posed significant challenges for healthcare organisations, as UK equality legislation requires public health sector organisations to offer equitable services to all people, regardless of ethnic or racial background (Equality Act, 2010). Understanding the diversity of service users (SUs) has become a significant area of reform in the National Health Service (NHS) (Wilson & Iles, 1999).

One-in-five individuals present to primary care services complaining of physical symptoms. Commonly, general medical conditions are ruled out after thorough assessments and investigations. The way in which patients and their condition are understood and diagnosed influences the interventions offered, the trajectory of their symptoms and their quality of life (Stone et al., 2010). Functional Neurological Disorder (FND) is an umbrella term used to explain a wide range of physical symptoms that resemble disorders of the nervous system without organic cause and often no physical health explanation is found (Reuber et al., 2007). Common symptoms or signs include but are not limited to seizures, motor symptoms (e.g. dystonia, limb weakness or gait disorders) and sensory symptoms (e.g. visual impairment or numbness) (O'Connell, 2019). FND has roughly been reported to account for 5-10% of new neurological consultations, with 8,000 new diagnoses a year in the UK (Carson & Lenh 2016).

FND has been described as ‘lacking ownership’ and with the needs of many patients falling between neurology and psychiatric services (Rommelfanger et al., 2017).

Misdiagnosis and inappropriate interventions carry risk of further illness, iatrogenic injury and cost to patients and healthcare systems (Birmingham et al., 2010; Reuber et al., 2004).

Yet, services designed to support individuals with FND are limited, with patients often experiencing endless rounds of referrals and re-referrals. Frequently, when a diagnosis is offered, it is poorly explained to the point where patients are left feeling their symptoms are not real (Cock & Edwards, 2020).

Traditionally, there have been several theories pertaining to the aetiology of FNDs with the most common explanation considering the role of psychological distress or trauma (Fobian & Elliott, 2019). Whilst there is evidence to support this theory, research in this area is scarce and studies have indicated that individuals often respond negatively to a psychological explanation for their somatic symptoms (Fobian & Elliott, 2019). There are multiple influences that shape an individual’s understanding and experience of their symptoms and distress. These influences can include culture, family and community, early life experiences, and faith (Moleiro, 2018). Whilst it is understood that these influences are not synonymous, it is recognised that they can influence and create unique cultures for individuals (Moleiro, 2018). Psychological distress in many non-Western cultures and faiths is communicated through somatic complaints such as stomach pains, headaches and fatigue. This is often an acceptable means of expressing and experiencing distress in many non-Western cultures where psychological difficulties are stigmatising (Mehraby, 2009). Most recently, psychological factors have been removed from the diagnostic criteria of FNDs with diagnosis involving checking for signs of FND during initial examination, rather than treating it as an afterthought when all other possibilities have been ruled out (Garcin et al., 2017; Cock & Edwards, 2018). This shift in diagnostic criteria for FNDs reflects the current

research which indicate heterogeneous predisposing and maintenance factors of FNDs (Fobian & Elliott, 2019).

Research indicates that individuals and their families find the diagnosis of FND difficult to understand and the transition from a physical health setting to mental health services challenging (Kozłowska et al., 2018). This transition may be even more confusing and distressing for individuals from Black and Asian backgrounds who can experience distress in terms of physical symptoms (Mehrabiy, 2009). Furthermore, this becomes even more challenging given the everyday experiences of Black and Asian individuals being stigmatized and experiencing poorer health outcomes. Racism is acknowledged as a social determinant of health and a catalyst for health disparities (Hackett et al., 2020). Racism is a multifaceted, organised system that is rooted in socio-political and historical contexts. The categorising of ethnic groups into social hierarchy drives disparities in access to opportunities, power and resources (Williams & Mohammed, 2013). Racial discrimination has been linked to poor health, increased psychological distress, reduced life satisfaction, and poor mental and physical functioning (Hackett et al., 2020; Wallace et al., 2019). Given existing racial health inequalities in the NHS and the limited understanding of FND, it may be that individuals belonging to particular ethnic, cultural and faith groups do not access or benefit from mainstream FND services and treatments due to differing understandings of their condition or experiences of accessing services. Cultural upbringing, religious understandings and wider held cultural and health beliefs may influence the experience of their condition.

Rationale for research

To the researcher's knowledge, there are no known studies exploring cultural and faith-based experiences of having an FND. This study will provide an insight into the experiences of individuals from Black, Asian, and faith-based backgrounds with FND in

terms of understandings but also experiences of services. This understanding is significant as individual perceptions of difficulties has been shown to affect adjustment to the condition, acceptance of interventions and treatment outcomes (Horne & Weinman, 1999; Petrie et al., 2002).

Aims

The overarching research aim was to explore whether family/faith/culture play a role in the experience of FND in Black and Asian cultural and faith-based groups. There are four particular aspects of this experience that are of interest to the study:

1. How do individuals who have faith and/or are from a Black, Asian or Minority Ethnic cultural background experience their FND?
2. How do individuals with faith and/or a Black, Asian or Minority Ethnic cultural background understand their FND?
3. What is their experience of treatment for their FND (if any)?
4. What are participants' experiences and responses to their family's/friends'/closest community's understanding of their FND?

Methods

Design

This study carried out semi-structured interviews using Interpretive Phenomenological Analysis (IPA) (Smith et al., 2009). IPA is concerned with how individuals make sense of their experiences. This was chosen to allow for a more in-depth exploration of the experience of individuals from a Black and Asian background who experience a faith and who are experiencing functional neurological type symptoms. IPA is positioned between critical realism and 'strong' social constructionism. The researcher adopted this position which means that the individual constructs the 'lived world' as an example of subjective reality, while also maintaining that certain aspects of that reality are fixed (Willig, 2012).

Participants

Participants were recruited using opportunity sampling from social media sites such as Twitter and Instagram. A total of seven participants were recruited this is seen as an appropriate sample size for IPA (Smith & Osborn, 2003). Inclusion criteria to take part in the study included: identifying as being from a non-Western, or non-white background, following a faith, and experiencing functional neurological symptoms, 18 years or older and being able to speak English at a level to engage in an interview (see Table 1 for participant demographic information). As there are no studies exploring cultural and faith-based understandings of FND and given the breadth of experiences between individuals from different cultural and faith groups, the inclusion criteria were deliberately kept broad to capture a range of understandings and experiences. However, the final sample was less broad than intended and was naturally made up of individuals from Black and Asian backgrounds from who largely followed a Christian or Muslim faith.

Table 1.***Participant demographic information***

Participant	Ethnicity	Faith	Age	Gender	Years experiencing symptoms	Diagnosis	Understanding of symptoms
P1	Baluch	Muslim	32	Female	2-5 years	NHS: Anxiety, stress Spiritual: Possession Magic/ witchcraft and evil eye	Spiritual
P2	Caribbean	Christian	49	Male	5-8 years	FND	Medical
P3	Pakistani	Muslim	44	Female	< 1 year	FND	Medical
P4	Mixed Caribbean and South Asian	Spiritual	25	Female	5-8 years	FND, motor tics	Medical
P5	Caribbean	Christian	44	Male	5-8 years	FND Gait disorder	Holistic
P6	Bangladeshi	Muslim	29	Male	< 1 year	FND	Spiritual and Medical
P7	Mixed – Caribbean and white British	Christian	25	Female	5-8 years	NEAD ¹	Medical

¹NEAD – Non Epileptic Attack Disorder

Procedure

An advertisement (Appendix D) was circulated via social media platforms Twitter and Instagram, which outlined details of the study and contact details for the researcher. Individuals who expressed an interest via direct message or email were sent a participant information sheet (PIS) (Appendix E) and consent form and were offered the chance to ask questions. The PIS included a weblink for a screening questionnaire (Appendix G) for participants who were still interested in going ahead with the study. The researcher contacted participants who met the eligibility criteria and invited them to a Zoom interview. Consent forms were emailed to the researcher before the start of the interview.

Interviews

The interview schedule (Appendix I) was developed under supervision from the research supervisor and in consultation with an expert by experience (EBE), who was from a Black British background and had recently received a diagnosis of FND. The EBE had a background in research and was employed by an NHS trust; the researcher was connected with the EBE through the university. The appropriateness of the questions were appraised and changes were made before being used with participants. The interview schedule included broad open-ended questions to give participants opportunity to talk about their experiences in their own words (Smith et al., 2009). The schedule was based on the research questions to provide focus. Given that some of the participants experienced speech difficulties and fatigue, all participants were given the option to complete the interview over one or several meetings. Most participants completed the interview in one session and interviews lasted between 60-100 minutes. Participants were reminded of the limits of confidentiality and their right to withdraw at any time. It was also agreed at the start of the interviews that the researcher would alert participants to when a natural break arose in case participants wanted to stop. It was also agreed that should participants need a break before this point, to alert the

researcher. All interviews were audio recorded using a Dictaphone, uploaded to a secure password protected laptop and transferred to an encrypted memory stick. The interviews were transcribed verbatim and confidential details were removed or altered. Anonymised transcribed interviews were kept on a password protected laptop. All anonymous transcripts will be securely stored for ten years.

Data Analysis

Interviews were transcribed verbatim, and data were analysed in line with IPA protocol (Smith et al., 2009). The researcher analysed each transcript before moving onto the next. This process involved reading and re-reading of transcripts to gain familiarity with the data, noting down descriptive, linguistic, and conceptual comments. Emergent themes were formed through considering the connections and patterns in exploratory comments. To create more defined themes, similar themes were grouped together. The researcher then compiled the themes from each participant in order to identify patterns among them, resulting in superordinate and subthemes. The process of analysing the data was not linear and transcripts were continually reviewed.

Quality assurance and reflexivity

To ensure quality of the research, the researcher used best-practice guidelines for qualitative research (Yardley, 2000). Prior to conducting interviews, the researcher conducted a bracketing interview with a colleague. This enabled the researcher to reflect on some of her own assumptions and biases, which included an assumption that discussions would be centred around cultural or faith-based understandings of symptoms, and the participants' experiences of these. A reflective diary was also kept throughout the course of the study to note any key emotional processes and its potential influence on the study (Appendix J). To ensure methodological rigour, the researcher followed guidance from Smith et al. (2009). An

annotated transcript was cross checked with the lead supervisor, evidencing substantial overlap in interpretation and further opportunity to discuss researcher biases. Furthermore, the integrity of findings was maintained through continuous comparison of emerging themes alongside the transcripts. All themes in this study were grounded in data, in the form of example quotes. Appendices have been included to document theme development with further examples of quotations (Appendix L, M and N).

Ethical considerations

Ethical approval was gained through Salomons ethics committee (Appendix C). Participant responses were anonymised for purposes of confidentiality. Given the social characteristics of participants and the small numbers, additional consideration was given to ensure that quotes remained non-identifiable. A signposting information sheet with contact information for related organisations was provided to each participant (Appendix H).

Results

This study aimed to explore the role of culture and faith in the experience of FNDs. Whilst each participants' experience was unique, three superordinate themes, each with subthemes, were identified by the researcher (Table 2).

Table 2.

Superordinate Themes and Subthemes

<i>Superordinate themes</i>	<i>Subthemes</i>
A cycle of mistrust	Others needing to see to believe Socialised norms Evolving views of services
Navigating the labyrinth	Making sense of symptoms Mystery in diagnosis mirroring mystery in services Knowledge is power Lonely journey Double stigma
Having faith in faith	Not being completely alone Faith in uncertainty Healing in faith

Superordinate Theme: A cycle of mistrust

This superordinate theme describes how mistrust plays a part in participants' experience and management of the symptoms, summarising the interplay of experiencing a lifetime of systemic racism, experiencing symptoms of a niche condition and the stigma of the symptoms being labelled as a mental health condition. There are three subthemes: others needing to see to believe, socialised norms, evolving views of services.

Others needing to see to believe

This subtheme captures the experiences participants had of others' doubting the genuine nature of the symptoms, questioning participants' understanding of the symptoms and the impact of them. This subtheme also captures many participants' experiences of having to 'prove themselves', leading to a cycle of seeking reassurance, not getting reassurance, and internalised self-doubt.

“There's even big doubts about whether the seizures are real, whether I'm putting them on”

(P7)

For others, they found themselves having to prove their ability by trying out the different suggestions offered by friends, family and services. At times, this appeared to bring doubts into the participant's own mind about their experiences.

“When I'm doing these things and it's not working, I have to prove to them, that anything they say to me, I have to try it for them to realise the extent to what I can't do... there's friends I've lost because they don't really believe what's happened” (P2)

Participants described feeling desperate at times in their attempts to be believed and to be provided with compassionate care, leading participants to record their experience of their symptoms to provide evidence to healthcare professions, as well as recording their interactions with professionals.

“And from that point on I started recording things, so I recorded the conversation, and I would delete after...if it's ok. Cos I'd keep getting this thing where people wouldn't believe what I'm saying” (P4)

Socialised cultural norms

This subtheme captures the experience of how family stories interacted with participants' own sense-making of their experiences, help-seeking, and help-receiving. This subtheme captures levels of mistrust within each of these, with strong narratives around being cautious about how much gets shared with others, through to experiences Black and Asian individuals had, learning that their journeys in life would be more challenging than their White peers.

“There's this huge thing about you don't talk about things, you don't share... ideas about what and can't be shared are very strong...I didn't talk about it, so it's always been a closed lip situation” (P3)

Participants also spoke about experiences that have been passed on and shared in families relating to racism and oppression which had led to feelings of mistrust in statutory services. It appears that a lack of attentiveness to participants' individualised understandings of the world and illness led to these families rejecting Eurocentric understandings that are commonly applied.

“He's [P4's father] had all the experiences of racism and stuff. So he's very much set in this, White people don't know what they're talking about and erm these doctors don't know anything that they're talking about.” (P4)

Participants reflected on how their upbringing may have influenced how they managed their difficulties. They described a narrative of ‘just keep going’ and perhaps not revealing vulnerabilities to others. Within this, floated ideas around ‘choice’ and ‘options’, many of the participants alluded to feeling that they did not have the choice or option to slow down and recover.

“My work ethic and arguably, cultural background as well as my parents’ influence, is that I will keep going, and I just keep going until I go and collapse. And I’ll keep going again because I see that I’m actually fit and perhaps the other person [speaking generally about others] isn’t” (P5)

Participants also spoke about learning to tolerate societal prejudices and the messages that are constantly reinforced throughout society. Socialised experiences of the distress of Black and Asian individuals remaining fundamentally unseen appeared to be reinforced in participants’ journeys.

“As soon as I leave the front door I’m judged by my colour, straight away. Don’t look in the eyes of the police because if you look at them they will actually stop you and give you a question. You tolerated the society so your compensation mechanism for tolerating the world and all your adversities that you have through work and stuff like that, that is you, that is ingrained. It’s passed from your parents and then society will reinforce all of those.” (P5)

Socialised norms also related to how friends and family at times struggled to understand the participants’ diagnosis or view of symptoms based on their own world view and experiences.

“How can stress make you, you know fall on the floor and collapse, and start jolting...It’s difficult for them to get that, that stress can actually manifest into these symptoms.” (P7)

Finally, socialised norms related to participants’ awareness of their use of language to describe their symptoms and understanding and its implications when there are power imbalances and further, having to adapt or assimilate to seem more acceptable in mainstream, Eurocentric understandings.

“I describe all the symptoms for example, I shake and black out, I can’t think and I feel heavy, and I experience involuntary movements and this and this and this but I won’t say, because I think it’s jinn possession. I won’t say that. Because I don’t want them to think I’m experiencing psychosis and then take my kids from me or something.” (P1)

Evolving views of services

This subtheme relates to the experiences participants themselves or friends and family have had with services and how this relates to participants themselves seeking support. It also captures the evolving view of doctors and services, from trust to lack of confidence in services due to several unhelpful interactions and experiences.

“I think once upon a time doctors were considered gods, no, you can make just as many mistakes and you are just as fallible.” (P5)

It ties in with mistrust in that it appeared that participants had learned that professionals were not always there to help, leading to individuals adapting by becoming self-resourceful and managing their symptoms themselves.

“Because you’ve grown up thinking they’re your friends, but they’re only your friend if they want to be your friend.” (P2)

Questions were raised by some participants as to why they were prescribed several different medications which had little effect on their symptoms. For some, there was a sense that medication had been prescribed to silence them, which may have influenced individuals’ attitudes toward services.

P2: “You question why you get given the medication.”

Researcher: “Why do you think you got given the medication?”

P2: “To silence me.”

Health care professional (HCP) personal characteristics were highlighted by some participants as being important. There was a sense that representation would help participants feel more understood and more humanised in system where there were experiences of being disbelieved and dismissed.

“I used to moan to my friends that, she’s just a 25-year-old, she’s got no idea of life, she has no idea of what it’s like for me.” (P3)

One participant highlighted not finding services useful based on previous unhelpful experiences. This meant that they chose not to access services even when the symptoms had gotten worse.

“My wife did consider to take me to the hospital when the episodes were getting severe afterwards. But I just said no use, I know what they're going to do...So, I didn't, I didn't go.

Because I know, I have already had that experience before.” (P6)

One participant explained how the COVID-19 pandemic forced her to try out and have faith in the services offered. Despite her initial apprehensions, this appeared to be a helpful service for her and appeared to restore previously held beliefs of authorities and services not being there to support her. It was apparent that participants felt more able to share their experiences when the HCP was curious, warm and validating.

“As I got to know him [neuropsychologist] I opened up a bit more to him...It was my only outlet for two months. I surprised myself how much I'm able to share with him...He's not the kind of person I ever imagined I'd open up to, I've shared things with him that I've not shared with anyone else.” (P3)

Superordinate theme: Navigating the labyrinth

This superordinate theme consists of five subthemes which capture the participants' experiences of navigating the condition and the system (friends, family and healthcare system), these are: making sense of symptoms, mystery in diagnosis mirroring mystery of services, knowledge is power, lonely journey, and double stigma.

Making Sense of Symptoms

This subtheme reflects how participants made sense of their symptoms and the evolving nature of this. All participants had been through diagnostic investigations. Understandings can largely be captured under spiritual interpretations and medical interpretations.

One participant received a spiritual diagnosis of Jinn (spirit) possession, Sihr (magic/witchcraft) and Ayn and hasad (evil eye).

P1: "He (exorcist) said to me I have all three and that was the diagnosis that he gave me.

Researcher: Was that an acceptable diagnosis for you?"

P1: "Yeah because it describes what I was feeling because I felt possessed. These actions, these things were not me, it was involuntary, it wasn't me doing them. It was like someone else was doing them, taking over me, taking over my arm, taking over my mouth, my body. It wasn't me."

Another participant described holding both a medical and spiritual view of their symptoms, but that they had to turn to faith-based medicine because they had not received a response from NHS services.

"I would do (it: healing prayers) every day in the morning after Fajr (first prayer of the day), then after Asr (last prayer of the day)...I would say it did work out. but I don't know how."

(P6)

Despite the fact that it was not the diagnosis they desired many of the participants appeared to accept a diagnosis of FND.

“I understand it as erm the wires in my brain aren’t quite working and they’re sending down confusing messages and that all my subconscious and conscious thoughts are being jumbled up. And because brain knows there’s something wrong it’s trying to fix it, but it’s trying too hard which is where all of the emotional and physical symptoms come from.” (P3)

A few participants began to understand adverse experiences and earlier trauma as possible reasons for their symptoms.

“Emotionally, there’s been experiences in life they’ve just been life experiences that have just made me, me. I think this has made me realise that some of those experiences have had an emotional toll” (P3)

One participant reported an environmental hypothesis, reporting that repeated injury to the body lead to the development of his symptoms.

“The reason why they started was because we had moved to a new building...and I had issues with the ergonomics of the building...my ergonomics or my body of how I actually move, is completely different to everybody else.” (P5)

Mystery in diagnosis mirroring mystery of services

This subtheme captured the experiences of participants trying to make sense of their symptoms and diagnosis in a healthcare system where limited knowledge of FND existed.

Parallels appeared in participants' narratives when they spoke of navigating services and receiving an FND diagnosis.

“FND is not that well understood anyway... even the medical domain... On the first few instances, the duty doctor, and the people within the A&E, they just couldn't... make out... what's going on.” (P6)

Feelings of frustration arose in trying to find the right service and receive an explanation for the symptoms. It seemed as though participants were often searching for a needle in a haystack. There was a real sense of disappointment when participants were recalling their experiences. For some, this experience led to them second guessing the nature of their symptoms.

“It was like you're trying to look for this golden person who can tell you what's going on, because you're going to golden people, aka doctors and hospitals. No one can tell you, and you're thinking well if doctors can't tell you, who's going to be able to tell you.” (P4)

Knowledge is power

This subtheme speaks to complex power imbalances and interactions that influenced participants' experiences and understandings of their symptoms. Participants' spoke of biomedical dominance within their family's culture and the power of a doctor's opinion. There were parallels of this in their experiences accessing services and undergoing investigations. Participants also spoke about becoming self-sufficient by becoming knowledgeable in their own symptoms and conditions, this seemed to help them to advocate for themselves when accessing services. It appeared that this was done with the intention of

reducing burden for HCPs and ensuring they received the right support. It seemed that participants' knowledge at times may have led to participants being labelled as a 'difficult patient'.

"He was kind of rebuking me...he said 'why would a 45 year old guy be walking around with a walking stick?' So it's like as if he was saying to me that...I was faking it...And at that point I was just livid because he was refusing to do further tests, as far as he's concerned, he said there's no point doing any brain scan tests." (P2)

Participants spoke about how power imbalances were magnified when they desperately searched for answers and expressed a feeling of vulnerability that came with this process. It appeared that the lack of diagnosis also made participants vulnerable to exploitation by the systems around them for example, employers who largely requested a diagnosis or doctor's note.

"(gesturing) My tunnel vision goal was...just tell me what's going on. I hadn't even thought of treatment, management, medication, nothing, just something was going on please... I'll look it up myself if I have to, just somebody just someone tell me what's going on." (P4)

Participants also spoke of balancing power imbalances and challenging prejudices and stereotypes. It seemed that participants found themselves feeling empowered yet disempowered in a structure where power imbalances and biases prevailed.

“Because of my job, it probably even makes me completely annoying and really quite erm what is it, challenging, really challenging the ideas and the concepts because I'm a protein biochemist and I'm not in, I'm not absorbed in a psychiatric world.” (P5)

Participants also repeatedly spoke of being self-sufficient, *“I always like to try and gain some knowledge on stuff so I know what's going on with me.” (P4)*

Participants shared how helpful it was when they experienced compassionate, informative and collaborative care. Shared responsibility, understanding and decision making was found to be empowering and helped in how participants experienced their symptoms.

“I feel like they've all tried to work with me to help me understand and it's all been really good... Even when the professor was like I know another department before I even said what do I do...they haven't said right go and do this or...you need to do that, it's been very much with me.” (P4)

Lonely journey

This subtheme conveys the loneliness which appeared to engulf the everyday lives of the participants and their longing to be connected with and supported by others. All participants reported feeling isolated at some point in their experience because of their needs not being met, not feeling heard or understood, not being able to access the right support or because of stigma.

“I couldn't talk to my children they're too young, I couldn't look my husband. I had friends that phoned or text every week and I spoke to them, but they couldn't help me with my condition.” (P3)

Navigating services and the journey to receiving a diagnosis was at times a lonely journey for participants, with many of the participants having experiences of being turned away or discharged from services. It appeared at times that this was experienced as abandoning.

“There’s no one there for me to go back to or speak to, to say this is what’s happening, to get some sort of assistance. It does feel like that I’ve had to take on a lot of this myself and try to get through it myself.” (P7)

Reconciling the loss of role and former self was something participants spoke about. There was a sense that others were able to move forward while participants themselves were left behind or left to deal with their symptoms alone because of poor access to services and limited support.

“Also the frustrations of me having to grieve my old self. I’m having to instinctively learn and grieve at the same time... while trying to move forward. It’s overwhelming...and a lonely place because you can’t keep talking about that with the people around you.” (P2)

Similarly, participants reported feeling left to reconfigure themselves, their roles and goals.

“I want my life back, try just to do normal things because I can't drive, I can't cycle, I can't walk very far, I can't do a lot of things I used to do. The feeling of being trapped at home is very strong.” (P3)

Double stigma

This subtheme captured the complexity of navigating and coming to terms with living with debilitating symptoms while navigating the different English systems as a Black or Asian individual. Being an ethnic minority within a minority system (falling between the cracks of neurology and psychiatry) where both social and cultural stigma and prejudice shaped the participants' experience.

“I don't even wish it on anybody. Anybody. Because it's so debilitating, it's so, especially in a world where people don't understand it and don't believe it, and don't know what's happening to you... You can't go to work and say I've got you know jinn possession.” (P1)

Participants alluded to societal stigmas and narratives around psychological difficulties being located within the individual and thus becoming the responsibility of the person to manage for themselves. It seemed that participants at times experienced a fear of stigmatisation and being left to manage alone, the difficulties.

“I didn't wanna think that it was something psychological cos I feel like that simplifies it, that's the word, I feel like it simplifies it and like reduces it. And it becomes very, very like, oh then it's on you to sort out then, you've kind of got this going on, you're the reason why this is all going on, and you got these symptoms, so need to work on that bit.” (P4)

For many of the participants, a double stigma existed in that they may have learned not to show any vulnerability or fragility when experiencing difficulties and thus may present to services in 'non-traditional' ways. This appeared to disadvantage participants at times meaning that their suffering was questioned.

“I probably learned to look after myself and become very independent so quickly... I guess you think through stuff yourself, you're quiet in yourself, you're calm in yourself, you're controlled in yourself and so you don't represent anybody who has any problems or issues.

You present completely different.” (P5)

Cultural values and upbringing also interacted with how some participants presented to services and advocated for themselves. It seemed that cultural and family values around respecting elders and those in authority at times clashed with Eurocentric ways of engaging with the participants' care.

“I think it does affect like how I advocate for myself. Like especially in the beginning stages, yeah it made it harder for me to like, erm, be more assertive.... Because it was kind of the idea that we just... get on with this yourself, like don't expect too much, don't like sort of take...the emotions that are coming with it too seriously because you need to kind of get on with this. I think... within the culture of my house, within my home, in Jamaican culture like, with somebody with a level of authority, the way to show them respect sometimes is not question them. To not speak up, like speaking up in itself can be disrespectful so the way to show respect is sort of nod...you don't question them, you don't sort of like probe for more so

I think that's also played to part in how I am towards authorities.” (P7)

Superordinate theme: Having faith in faith

This superordinate theme consists of three subthemes which captures the significance of faith in many of the participants' lives. The previous two superordinate themes highlighted the significant distress and challenges faced by the participants in their journeys.

However, this superordinate theme demonstrates how faith provided empowerment and hope in what was a relentless journey for the participants. On a journey of uncertainty, it was apparent that the only certainty participants could have faith in, was their faith. There are three subthemes: not being completely alone, faith in uncertainty, and healing in faith.

“I think the accident had to happen. Erm I think if God asked me do I have a choice, I would’ve probably said no, but He knows best... by putting all my trust in God, allowed me to get to this stage.” (P2)

Not being completely alone

This subtheme captures a sense of safety and comfort participants’ felt within their faith. It appeared that for many of the participants, there was a desire to be held in mind, with many of them feeling that they were not entirely alone and that there was a higher power looking out for them. In an experience where participants experienced several losses, this appeared to bring a sense of safety and security.

“This whole journey that I’ve been on, it’s taken me to some dark places and I constantly would say those prayers when I... I just, I lived to sleep and lived to wake up and didn’t know why I was living because I couldn’t do nothing for myself. But I know that just by looking out the window and seeing the sun come up He [God] hasn’t forgotten me.” (P2)

“I strongly believe that because of my faith, you know ...there’s a small.... surah in the last chapter (of the Quran)...Usri Yusra (Arabic), so with hardship comes ease. And so, you always have that... forward thinking, you know, there is hope at the end of the tunnel, there is light at the end of the tunnel.” (P6)

Faith in uncertainty

This subtheme highlights how faith provided consistency and complete certainty in a journey that was unpredictable. This appeared to be important for participants and appeared to be a protective factor for many through their journey. This seemed to provide a sense of comfort, and perhaps alleviated a sense of isolation that was sometimes experienced. *“I guess actually, in the midst of all I was dealing with, He [God] was only thing that felt certain.” (P7) “When you feel helpless and you have faith, that is all you can do.” (P3)*

Healing in faith

This subtheme captured the emotional and sometimes physical healing participants found through their faith. Examples of this included engaging in healing prayers, going on a pilgrimage, or through listening to sermons, or just simply surrounding themselves with people who have strong faith. It seemed that faith offered a safe haven for individuals to escape the stresses of their lives, faith also provided acceptance in a world where they felt rejected. Through faith, participants appeared to find the strength to continue with their journey and at times reduce symptoms.

“My faith has really helped me through. Because, you know when you feel like, maybe I'm not being supported by my family, with people that are close to me that I'm looking to for like some guidance or support, assistance. I know that God is there, and that I can pray to Him, and I can talk to him, and feel comforted by him. And I don't know, if I didn't have that, I probably would have like, lost hope and I probably wouldn't have been able to go, to carry on with things that are so difficult.” (P7)

“I’m fighting through it and once I get my head down in sujood (prostration), and then I make dua (prayer) and I’m like Allah you’re greater than this and I just feel all that what’s inside of me vanish with that prayer.” (P1)

Discussion

This study explored the role of family, culture and faith in the experience of FNDs and Black and Asian individuals' experiences with services. Given the limited research on FNDs, this study contributes to current literature on the experiences of Black and Asian individuals experiencing symptoms of FND and the multifaceted nature of this. This study found that individuals did not go on the journey of making sense of their symptoms alone. They entered the journey with their personal histories, friends, family, culture, social context, and professional system. It found that both the individual's personal system and the healthcare system shaped the experience of symptoms in terms of maintenance and management.

The superordinate theme of 'a cycle of mistrust' demonstrated the evolving nature of mistrust and the various types of struggle experienced by the participants, including the struggle of being disbelieved by individuals in their own system as well as by the professional system, of concealing thoughts and feelings, not appearing vulnerable and internalised ideas of working hard to achieve a goal, or in this case, to receive answers. The presence of a good social support network has long been shown to have direct positive effects on physical and mental health outcomes by acting as a buffer (Che et al., 2018; Ozbay et al., 2008). This study found that social support networks appeared to be a source of both comfort (e.g. providing advocacy, practical and emotional support) and distress (e.g. doubting the genuine nature of symptoms and offering differing hypothesis to the individuals') for participants. These observations concur with wider literature on Black and Asian individual's experiences of similar chronic long-term conditions (Bashir et al., 2016).

The superordinate theme 'navigating the labyrinth' showed the complications and challenges participants experienced in their journeys. Despite cultural norms on symptom

management, help-seeking and historical experiences of prejudice from those in authority, participants were open and interested in exploring their symptoms from a Eurocentric framework, however, this was a very difficult journey for many. Research has shown that misdiagnosis of FND is detrimental to prognosis (Barnett et al., 2020). Only one participant in this study experienced timely access to services, diagnosis, and intervention. Reports of experience of FND, understanding and management of symptoms were largely positive for this participant. This reflects the literature which indicates that clear explanations of diagnosis, legitimising of patients' experiences and presenting clear evidence of how their symptoms contributed to making the diagnosis can also have a positive therapeutic effect and enhance outcomes (Stone et al., 2005; 2016). Unfortunately, this was not the experience of all individuals with many of the participants reporting waiting years to access the right support and receive a diagnosis. This appears to reflect experiences more broadly where patients with FND are often stigmatised by HCPs who feel patients are 'putting it on' which leads to patients not being taken seriously and not receiving appropriate care (Barnett et al., 2020).

All participants reported feeling alone at some points in their journey. This appeared to be connected to the double stigma individuals faced. Firstly, the social stigma of their physical symptoms being labelled as 'psychological' and the challenges and lack of understanding on the part of others that come with this, and secondly navigating a complex system as a Black or Asian individual. Recent research found three forms of stigma to be highly present in experience of FND: healthcare and public, self, and avoidance of the label itself (Rommelfanger et al., 2017). Authors explained how lack of knowledge, fear, avoidance, and discomfort from HCPs can lead to patients internalising such ideas towards their own experiences which can lead to a rejecting of support. Though the experiences of participants initially appear to reflect that of wider experiences of FND, it is important to note the element of minority stress in the experiences of the participants in this study. Prejudice

and stigma create additional constraints to the agency of individuals already oppressed by systematic hardships. Discriminatory practices from this perspective, become stressors that preserve prejudicial victimization, further disenfranchising the person in their ability to draw on their strengths and resources (Prilleltensky, 2003). Furthermore, such stigma compromises resilience in those who are oppressed as it exacerbates external circumstances designed to hold them back as well as turning bias inwards as reported by some participants in this study (Hobfoll, 2004; Palmer et al., 2019).

Cultural values and upbringing influenced how participants made sense of the severity of their symptoms as well as how they presented and related to HCPs. Cultural determinants play an important role in mental health help-seeking. The cultural determinants of Arnuat's (2018) help-seeking model provides a method of understanding meaning-making and the setting of expectations through people's cultures, upbringing, and social context. This study highlights the complex interplay between cultural norms and Eurocentric ideas, individuals were frequently balancing cultural and medical explanations for their difficulties. Though participants were open to Eurocentric ideas, how this was approached was found to be key. For instance, participants described positive interactions as those where the HCP was curious, validating, and informative. Unfortunately, this was not always the case for participants, with some participants even reporting that they did not return to services due to unhelpful experiences.

The superordinate theme having faith in faith highlighted the significance of faith in individuals' journeys. Holding faith emerged as a significant factor in promoting management of symptoms, connection, and resilience. It became clear that participants' beliefs and practices offered a huge amount of psychological support and sustenance. This reflects the wider literature which has shown religious coping (e.g. prayer) to be protective

for physical and mental health outcomes such as, reducing symptom severity, feelings of anxiety and the number of days spent in hospital (Clements et al., 2019; Coruh et al., 2005).

Limitations

The findings from this study offer insights into the experience of Black and Asian individual's experiences of FND symptoms however, they are not intended to be accurate predictors of experiences in the general population. This is not only limited to IPA methodology but also due to intersectionality, and thus the experiences are unique to each individual. Furthermore, the results are limited to a single interpretation, which was most likely shaped by the researcher's history, experiences, and beliefs. Consequently, it is probable that a different researcher may have emphasised different aspects of the participants' accounts, highlighting different interpretations. Nonetheless, efforts were made to safeguard the research process through engaging in critical reflection throughout in addition to engaging in discussions with colleagues and supervisors which helped to ensure findings were grounded in the data.

Participants were recruited via social media platforms such as Twitter and Instagram, and self-volunteered, as such the role of selection bias cannot be ruled out. Furthermore, the title of the study could have attracted individuals who felt able to share their journey and who felt culture and faith played a role in their experiences. Additionally, almost all individuals shared positive experiences of faith, the title of the study and wording of the inclusion criteria may have biased participants more in this direction.

Clinical implications

The current findings have important implications for clinical practice. All participants were open to accessing healthcare services and to hearing explanations offered by HCPs. However, lack of knowledge, rigid hypothesis, prejudice and stigma from HCPs and from

their social support network led to individuals experiencing a loss of autonomy and power. Stigma related to diagnosis and race was apparent in individuals' experiences where many of them reported being disbelieved in parts of their journey. It seemed that participants had internalised stigma related to their FND, this may have brought up previous similar experiences (Quinn et al., 2015). Lack of knowledge of FNDs and stigma meant that individuals were often left to research and manage their symptoms alone. The impact of structural racism on racial health inequalities are widely documented (Razai et al., 2021) and to ignore the potential influence of this for Black and Asian individuals navigating and accessing services would be a significant omission. In order to increase health equity, it is vital that Black and Asian individuals' feel heard in services and that their experiences are validated. Awareness of stigmatised views can lead to lack of trust in HCPs (Barnett et al., 2020). Participants in this study reported feelings of hostility from HCPs. Patients are less likely to take on board the diagnosis or treatment strategies if they feel disparaged by their HCPs (Barnett et al., 2020). A study with HCPs demonstrated that HCPs avoided patients with a diagnosis of FND due to lack of confidence in offering support and so passed them on to another discipline (Barnett et al., 2020). This can lead to feelings of frustration and hopelessness in patients as found in this study.

Furthermore, research with HCPs has indicated that HCPs would like increased training and knowledge of FND and awareness of pathways from assessment to treatment to alleviate some of the uncertainties that currently exist (Barnett et al., 2020). The inclusion of teaching on FNDs in clinical training programmes could reduce some of these barriers. Awareness of idiosyncratic presentations and curiosity of how culture, socio-political context, and individual histories might influence experiences might also help to increase engagement and reduce distress. As evidenced by this study, people with FND have likely had negative experiences of services including being disbelieved. It is useful to spend time

listening to these experiences, learning more about the patient's understanding and what they and those around them would find most helpful now. Furthermore, it would be helpful to hear if participants have strong views about diagnosis, if a diagnosis is to be offered, how this is offered is crucial step in empowering patients.

Research implications

As this was the first known study to explore the experiences of Black and Asian individuals' experiences of FND, future research could explore themes that developed from this study, for example stigma and how this intersects with gender, race and FND. It would be interesting to compare males and females to learn more about the role of gender in stigmatisation. Such research may benefit from incorporating an intersectional approach, as the current research has demonstrated how it can highlight the complexity of Black and Asian individuals' lives.

Faith was found to be of huge comfort and support to participants, however, all participants in this study identified as either Christian or Muslim. Research into the impact of different faiths would be useful to see if different faiths equally play a supportive role. All participants in this study were second generation migrants and experiences of first-generation migrants might differ. Patient empowerment is key it appeared, that participants felt empowered by sharing their story and contributing to research. There are several useful support groups such as FNDhope with individuals who have ideas about research and expansion. It is important to include patients, families, and advocates to help drive research priorities.

Conclusion

This is the first known study to explore the role of culture and faith in the experience of FND and more widely, Black and Asian individuals' experience of FNDs. Cultural influences such as help-seeking behaviours, symptom and suffering perceptions, upbringing

and language were found to play a part in how one experiences FND. Stigma in perceptions of symptoms from family and friends and HCPs were found to have a negative impact on individuals' own perceptions of their difficulties. Existing stigma of FNDs was found to further debilitate individuals and in some cases, meant that participants did not return to services. Participants reported feeling isolated in their journeys but reported finding strength and hope in faith. It is clear that "one-size-fits-all" solutions fail to meet the needs of diverse communities. As such, recommendations have been made for HCPs to spend time hearing and learning more about the patient's understanding and what they and those around them would find most helpful now. Validating experiences and working with patient understandings is a key step towards therapeutic engagement and patient empowerment. Finally, as this is the first known study to explore the experiences of Black and Asian individuals, further research is needed to help meet the needs of culturally-diverse populations experiencing symptoms of FND.

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AYSHA L. BALOCH BSc Hons, MSc.

MAJOR RESEARCH PROJECT

SECTION C: Appendices and supporting material

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor in Clinical Psychology

SEPTEMBER 2021

SALOMONS INSTITUTE

CANTERBURY CHRIST CHURCH UNIVERSITY

Please note: Any identifying features have been removed to ensure anonymity and maintain confidentiality

Appendix A. Mixed Methods Appraisal Tool

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	<i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5. Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Appendix B. MMAT study appraisal table

Quantitative non-randomized studies						
Paper	Are the participants representative of the target population?	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	Are there complete outcome data?	Are the confounders accounted for in the design and analysis?	During the study period, is the intervention administered (or exposure occurred) as intended?	Additional strengths/limitations
Owiti et al. (2013)	Yes – clear descriptions of the setting, clinicians and SUs provided	Yes – the authors adapted the TACCT to create	No – low number of respondents (45%) on follow-up measure	No – no reports of accounting for confounders.	Yes – authors report that the intervention was	- Potential for social desirability bias - Unclear if outcome was associated with the

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Quant before and after study		their own measure Measure unvalidated			administered as intended	introduction of the consultation service - Did not track changes in individual clinicians
Quantitative descriptive studies						
Paper	Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measures appropriate?	Is the risk of non-response bias low?	Is the statistical analysis appropriate to answer the question?	Additional strengths/limitations
Rathod et al. (2020)	Yes – non-probability/ purposeful sample was used based on	Yes – high response from clinicians and service users	Yes – The questionnaire was designed by the authors based on	Can't tell – Disproportionately more clinicians than SUs took part. No	Yes – categorical data was produced and	- Self-selection bias - Responder bias

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<p>Cross-sectional study</p>	<p>inclusion criteria. Site feasibility screening was conducted to clarify the number and percentage of non-white staff/patients</p>	<p>A total of 2805 participants, 2450 clinicians and 355 patients</p>	<p>previous work in this area. Clinician and SU versions were developed. however, non-validated measures were used.</p>	<p>information about those who did not participate has been collected.</p>	<p>analysed appropriately using Chi-Square</p>	<p>- No information on those who did not take part + Accounted for potential moderating factors such as length of service, experience of working with minority patients, gender and ethnicity</p>
<p>Zeh et al. (2018) Cross-sectional study</p>	<p>Yes – 66 general practices in Coventry were contacted</p>	<p>Yes – clear descriptions of target population and sample provided.</p>	<p>Yes– measures were created by the first author in consultation with diabetes specialist, patient</p>	<p>Yes – although authors achieved a 52% response rate, the authors collected data on from non-</p>	<p>Yes – descriptive statistics and categorical variables</p>	<p>+ Accounted for differences between responders and non-responders</p>

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			representatives and a consultant in public health. The measures were piloted before being rolled out.	responders and reasons were given on non-response	presented in percentages	
Qualitative studies						
Paper	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of the results sufficiently substantiated by the data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?	Additional strengths/limitations

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<p>Burchill & Pevalin (2014) Case study</p>	<p>Yes – authors aimed to assess the dimensions of health visitor’s cultural competency when working with refugees and asylum seekers</p>	<p>Yes – In depth open interviews were conducted with health visitors</p>	<p>Yes – framework analysis involving interpretative thematic analysis was used.</p>	<p>Yes – quotes provided to explain justify the themes</p>	<p>Yes – clear links are evident between data sources, collection, analysis and interpretation</p>	<p>+ Aims clearly defined + Study procedures clearly discussed - Potential responder bias - Participant demographics not collected</p>
<p>Hussain et al. (2020) Case study</p>	<p>Yes – explores how a NHS trust’s initiatives on improving quality of services provided to ethnically and culturally diverse SUs – evaluates workforce</p>	<p>Yes – face to face semi-structured interviews were conducted</p>	<p>Yes – thematic analysis was used</p>	<p>Yes – quotes provided to explain and justify the themes</p>	<p>Yes – clear links are evident between data sources, collection, analysis and interpretation</p>	<p>- Researchers did not include details of topic guide and so it is unclear what participants were asked</p>

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	diversity initiatives and diversity training initiatives					
Vydelingum. (2005) Case study	Yes – explored nurses experiences of caring for South Asian patients in a medical directorate of a general hospital	Yes – focus groups were held	Yes – thematic analysis was used	Yes – quotes provided to explain and justify themes	Yes - clear links are evident between data sources, collection, analysis and interpretation	- No details of topic guide
Warnock- Parkes et al. (2010) Case study	Yes – explored cultural knowledge and practice adopted within a service to meet the needs of	Yes – semi- structured interviews were conducted	Yes – thematic analysis was used	No – no quotes were used, descriptive statistics and explanations provided	No – it is not clear how researchers went from conducting	+ Staff and SU perspective - No quotes provided to evidence results

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	ethnic minority patients			without the use of quotes	semi-structured interviews to providing descriptive statistics of responses.	Missing responses not accounted for Non English-speaking SUs excluded however, one of the interview questions asks about language needs being fulfilled - Responder bias – female interviewer in all male ward
Wilkinson & Randhawa (2012)	Yes – explores the concept of patient’s access to quality care from a care providers perspective	Yes – one to one semi-structured interviews were conducted	Yes – thematic analysis was used	Yes – quotes provided to explain and justify themes	Yes - clear links are evident between data sources,	- Did not record data on participant’s ethnicity and how this might influence interactions

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					collection, analysis and interpretation	
Mixed methods studies						
Paper	Is there an adequate rationale for using a mixed methods design to address the research question?	Are the different components of the study effectively integrated to answer the research question?	Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	Additional strengths/limitations

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Adamson et al. (2011)	No – reasons for using mixed methods not explained	Yes – results of semi-structured surveys and open-ended interview themes are integrated to answer the research question	Yes – quantitative and qualitative components discussed together	Yes – Divergences discussed	No Quant: 4/5 Qual:4/5 MM:2/5	- Quantitative and qualitative results not integrated, presented separated - Rationale for using mixed-methods approach not given by authors
Bhui et al. (2015) – Convergent Mixed methods study	No - reasons for using mixed methods not explained	Yes - qualitative and quantitative results are integrated to answer the research question	Yes – quantitative and qualitative components are brought together and discussed	Yes – No divergences reported	No Quant: 3/5 Qual: 4/5 MM:2/5	+ Various use of measures limits responder bias - No clear descriptions for how quantitative measures were analysed

Appendix C. Ethical approval from Salomons ethics committee

This has been removed from the electronic copy

Appendix D. Final social media advertisement

CALL FOR RESEARCH PARTICIPANTS

Are you from a **Black, Asian or Minority Ethnic background?** Are you from a **faith-based background, following a religion?** Are you **from both?**

Have you experienced any of the following or similar symptoms:
Seizure-like attacks without known cause, involuntary movements or muscle weakness, brain fog, sensory disturbances like feeling, seeing or tasting something that's not there or seems odd, and/or 'absent' periods of awareness?

Can you give 90 minutes of your time to participant in a one-off confidential interview?

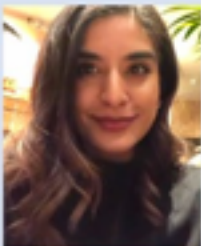
If you are based in the UK and ...

- Are over the age of 18
- Identify as being from a Black, Asian or minority ethnic or cultural background and/or follow a religion
 - Feel able to speak with a professional about your experiences
 - Speak English

...Then I am interested in hearing your story!

The aim of the study is to better understand the experiences of individuals identifying from a Black, Asian or minority ethnic or cultural or religious background's experiences of experiencing functional neurological symptoms. We hope by understanding the experiences of Black, Asian, minority ethnic and religious groups who have sought support or who have considered seeking support from mainstream and specialist services, we will be able to improve such services for particular groups in the future.

FOR MORE INFORMATION ABOUT THE RESEARCH OR RESEARCHER, OR TO EXPRESS AN INTEREST IN PARTICIPATION, PLEASE CONTACT AYSHA BALOCH: a.baloch1280@canterbury.ac.uk



Appendix E. Participant information sheet



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

Information about the research

Research project title: Experiences of functional neurological disorders: A faith and cultural perspective.

Hello. My name is Aysha Baloch and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. The study is being supervised by Dr Jerry Burgess, Senior Lecturer Research and Neuropsychology Lead at Salomons Institute for Applied Psychology, Canterbury Christ Church University, and Dr Jane Vinnicombe, Consultant Clinical Psychologist, Brain Injury Rehabilitation Trust.

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

You will be given a copy of the information sheet and a signed consent form to keep.

Part 1

What is the purpose of the study?

The purpose of the study is to understand the experience of someone who may have received a diagnosis of Functional Neurological Disorder (FND) or who has experienced non-epileptic seizures or similar medically unexplained experiences who also identifies as being from a Black, Asian or minority ethnic and cultural background, and/or follows a religion. We want to develop a better understanding how individuals from Black, Asian or minority ethnic and cultural backgrounds and/or individuals who follow a religion, understand this experience and what their experience of accessing NHS services has been.

Why have I been invited?

You have been invited to take part as someone who identifies as being from a Black, Asian or minority ethnic cultural background and/or follow a religion and may have received a diagnosis of a Functional Neurological Disorder (FND) or who has experienced non-epileptic seizures or medically unexplained experiences. We are looking for 15 participants to take part in the study.

Do I have to take part?

No. It is up to you to whether to join the study. You are free to withdraw from the study at any time, without giving a reason. You can also ask for your interview to be removed from the data (up to two weeks from the date of participating). This would not affect any of your statutory rights.

What will happen to me if I take part?

- You will be asked first to complete a short screening questionnaire; this will help me determine whether you are able to take part in the study.
- If you are invited to take part in the study, it would involve joining an interview using an online video call programme called Zoom. You would not need to have Zoom on your computer or phone – it just involves being sent a link so you can join the meeting. This would be just you and an interviewer and would be arranged at your convenience.
- The interview will be around 1 hour and 30 minutes in length

- You will be asked questions about your experience of having a Functional Neurological Condition and your journey so far, questions will involve thinking about your family, culture and faith if you follow a religion.
- In the interview, you would not be asked to share any feelings, beliefs or actions you do not feel comfortable sharing.
- The interview will be recorded and then a transcript of the recording would be written up.

What are the possible disadvantages and risks of taking part?

It is possible that previous experiences of having your feelings, beliefs or actions misunderstood, may have had a negative emotional impact on you. Remembering and discussing these experiences may have a similar emotional impact. It may also be that you begin to experience some of your symptoms during the interview, if you do decide to take part, we would advise telling someone you trust that you are taking part in the interview whom you can call on for support if needed. Please feel free to discuss with someone you trust whether you want to take part and how it might affect you.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help understand the impact for people of having a functional neurological condition, from different cultural and faith-based backgrounds.

Part 2

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

- If you decide you don't want to carry on with the study, we would like to be able to use what you've said up to the point you decided not to continue.
- However, you may ask for the data collected to be removed from the study *up to two weeks following the date of your participation in the interview.*
- If you decided this, the recording of the interview and any transcription would be deleted.

Concerns and Complaints

If you have a concern about any aspect of this study, you should ask to speak to me, and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070*. Please leave a contact number and say that the message is for me, Aysha Baloch, and I will get back to you as soon as possible. Alternatively, you can contact me via email at A.Baloch1280@canterbury.ac.uk.

If you aren't happy with the response and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology. His email is fergal.jones@canterbury.ac.uk.

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

Yes. All information which is collected from or about you during the course of the research will be kept strictly confidential, and any information written up will have personal identifiers removed so that you cannot be recognised. The following information is about protecting your information throughout the study:

- Data from group discussions and interviews will be collected and stored on an encrypted USB, password protected laptop and will be uploaded to Office 365 OneDrive and deleted from the device.
- Recordings and written material will be stored securely in Office 365 OneDrive. You can find information on Office 365's security standards at <https://support.office.com/en-us/article/How-OneDrive-safeguards-your-data-in-the-cloud-23c6ea94-3608-48d7-8bf0-80e142edd1e1>
- Written material would be stored separately from anything that might identify you to ensure anonymity. A different name would be used in the final written piece to promote confidentiality.
- Anonymised data will be retained for a period of 10 years. This is based on advice given by the Medical Research Council. After this time, the data will be securely disposed of.
- The only time when I would need to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else.

What will happen to the results of the research study?

The results will be written up in a report submitted to Salomons Institute for Psychology as part the assessment of my doctoral training. The report will also be prepared to be submitted to a research journal for publication. Quotes from group discussions and interviews may be included in reports or presentations but would be fully anonymised. If you wanted a copy of the report, I would send an electronic copy after it's accepted by the university.

Who is sponsoring and funding the research?

The research is sponsored and funded by Canterbury Christ Church University.

Who has reviewed the study?

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

Further information and contact details

Thank you for taking the time to read this information sheet. If you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me, Aysha Baloch, and leave a contact number so that I can get back to you. Alternatively, you can contact me via email at a.baloch1280@canterbury.ac.uk.

Date: 28th August 2020
Version number: 1

If you are still interested in taking part, please complete the short screening questionnaire:

https://cccusocialsciences.az1.qualtrics.com/jfe/form/SV_bq4NwdXfS7EGpCd

***Please note the 24-hour voicemail phone line is managed by university's admin team and all messages will be passed onto to me via a member of the admin team.**

Appendix F. Consent form



Participant Identification Number:

Name of Researcher:

CONSENT FORM

Title of study: Experiences of Functional Neurological Disorders: A faith and cultural perspective

Please initial box

- 1. I confirm that I have read the information sheet dated 30.03.20 version 1.0 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that participation of myself is voluntary and that I am free to withdraw within two weeks of providing consent without giving any reason, without my legal, dignity, or access to treatment rights being affected.
- 3. I understand that if I chose to withdraw from the study early, all information collected about me after the two-week deadline, will remain as part of the study.
- 4. I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 2018.
- 5. I understand that the information collected about me may be used to support other ethically approved research in the future and may be shared in already-anonymised form with other researchers including supervisors supervising the research.
- 6. I understand that data collected during the study may be looked by supervisors supervising this project. I give permission for these individuals to have access to my data
- 7. I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings
- 8. I consent to being audio recorded.
- 9. I agree to take part in the above study.
- 10. I would like to receive a summary report of the final project. YES NO

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Appendix G. Screening questionnaire

Screening questionnaire

Start of Block: Default Question Block

Q11 Thank you for your interest in taking part in a study looking to understand Black, Asian and minority ethnical cultural or faith-based groups views towards experiencing a functional neurological condition or medically unexplained experiences. Please complete the following questionnaire. The questionnaire will help me to assess if this is the right study for you to share your views. Therefore, you may or may not be invited to participate in the study. All information in the questionnaire will be stored securely and only used anonymously in the study report. The information provided in this questionnaire will not be kept and will be destroyed If you are NOT selected to take part in the study.

Please contact a.baloch1280@canterbury.ac.uk if you have any further questions.

Q13 Name

Q14 Email address

Q15 Gender

Q16 Nationality

Q1 Are you aged 18 or over?

- Yes (1)
- No (2)

Display This Question:

If Q1 = 1

Q18 What is your age?

Display This Question:

If Q1 = 2

Q20 Thank you for your interest in this study, unfortunately you are not eligible to take part currently as you are under 18 years old. You do not need to continue with the rest of the questionnaire.

Q2 Do you follow a religion?

- Yes but do not actively practice (1) |
- Yes - actively practice (2)
- I believe there is a 'God' or a 'higher power' but do not subscribe to a particular religion (3)
- No (4)

Q3 How would you describe your cultural and ethnic background?

Q4 Do you experience any of the following symptoms: functional seizures, involuntary movement, paralysis and weakness, sleep disturbances, brain fog, speech problems, sensory and visual disturbances?

Yes (1)

No (2)

Q5 Have you received a diagnosis or been told you have Functional Neurological symptoms? This might sometimes be known as Functional Neurological Disorder (FND), Functional Movement Disorder (FMD), Conversion disorder. This may include experiencing symptoms such as: functional seizures, involuntary movement, paralysis and weakness, sleep disturbances, brain fog, speech problems, sensory and visual disturbances.

Yes (1)

No (2)

I'm not sure (3)

Q6 Have you previously accessed NHS services for function neurological symptoms or are you currently accessing NHS services for your symptoms?

Yes (1)

No (2)

Q7 Has your understanding of your condition changed since you started accessing services?

Yes (1)

No (2)

Q8 Could you please provide brief details of the experience below

Q9 Do you feel that discussing your experience of your difficulties and your journey to date would cause you distress?

- Not at [all](#) (1)
 - [Somewhat](#) (2)
 - [Mostly](#) (3)
 - [Completely](#) (4)
-

X If you answered mostly or completely to the above question, you might wish to reconsider taking part in the study or arrange to speak with someone you trust following group discussion or interview.

Q10 If you are not invited to participate in an interview, would you be interested in receiving a summary of the findings of the study?

- [Yes](#) (1)
- [No](#) (2)

End of Block: Default Question Block

Appendix H. Signposting information sheet for support services



Thank you for attending the interview today, your time is valued. If you have any queries or concerns regarding the interview please contact the lead researcher Aysha Baloch (a.baloch1280@canterbury.ac.uk).

If you feel the interview has caused you any distress, you can access support through the following:

- Samaritans (www.samaritans.org; Telephone: 116 123)
- Mind (www.mind.org.uk)
- FND Action (www.fndaction.org.uk)

If you feel you are in need of urgent support, you can contact your local NHS crisis service (you can find contact details for your local mental health crisis team here: <https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline>) Or you can visit your local A&E department where support will be available.

Appendix I. Interview schedule



Interview guide

The first set of questions will be asking about your experiences

1. Could you describe your difficulties for me? Is there an expression or term you or people around you use to describe your difficulties?
2. Do you have a sense of when your difficulties started? / (Prompt question: What are your views on why your difficulties start when they did? What do you think caused the difficulties? / Are there any other causes that you think played a role?)
3. What impact have the difficulties had on your life? / How would you say things have changed for you, if at all?
4. How do your friends and family members understand your difficulties?
5. Do you follow a faith? (If yes, has faith been important for you during this time? Could you tell me more? Further prompt question: Has your faith helped you to manage your difficulties? Could you tell me more?)
6. What support have you sought if any for your condition? (FU Q: If you went to see a helper or healer of any kind, tell us about your visit and what happened afterward. / If you went to see a doctor, tell us about your visit to the doctor and about what happened afterward)
7. Is there anything else you would like to tell us about your experience of the difficulties?

The next set of questions will be asking about your experiences of accessing services for your symptoms.

1. Have you accessed any NHS support for your difficulties? Could you tell me more about your experiences? / How did you come to be referred to the service? (Prompt question: what are your views on this? Did you receive a diagnosis? How do you understand this?)
2. Could you tell me about your journey with the service, has it met your expectations? (Prompt questions: Did your health professional provide you with any treatment, medicine, or recommendations to follow? / Do you / Are you able to follow the treatment or recommendation or medicine?)
3. How did the health professions describe your symptoms?
4. How did you feel about the explanations provided by the health professionals you have seen?
5. What have you found helpful, if anything?
6. What has been unhelpful, if anything? / What do you feel the main challenges have been?



- 7.** Do you have any suggestions on what would be/have been helpful? / Were there any treatments that you expected to receive for your difficulties that you did not receive?
- 8.** How would you describe your difficulties now? / Has this changed?
- 9.** How have your friends and family responded to you seeking support? / Do they know you've sought support?
- 10.** Have you sought out any other therapy, treatment, help or care since you have been in (name of service)? (If yes, could you tell me more about this?)
- 11.** What advice and suggestions are you getting from family, friends, and laypeople with whom you may have discussed your difficulties (either directly or indirectly)?
- 12.** If participant has stopped attending services: What made you decide to stop attending the service?
- 13.** Is there anything else you would like to add?

Appendix J. Excerpts from reflective diary

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Appendix K. Coded transcript

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Appendix L. Stage 1 Individual superordinate and subtheme development process

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Appendix M. Stage 2 Group theme development

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Appendix N. Final superordinate themes and subthemes with quotes from participants

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Appendix O. End of study letter to Salomons Ethics Panel

Dear Chair of Ethics Committee,

Study title: ‘With Hardship Comes Ease’: Black and Asian individuals’ experiences of Functional Neurological Disorder

I am writing to inform you that the above research project is now complete, and a thesis has been written for submission in partial fulfilment of the degree of Doctor of Clinical Psychology at Canterbury Christ Church University. I have included a brief summary report for your information.

Background: One in five individuals present to primary care services (e.g. GP or A&E) describing physical symptoms such as non-epileptic seizures, dystonia, limb weakness, walking difficulties, visual impairment, numbness, headaches and paralysis. One way of understanding the collection of these symptoms is under the diagnosis of a functional neurological disorder (FND). Research indicates that individuals and their families can find the diagnosis of FND difficult to understand and the transition from a physical health setting to mental health services challenging (Kozłowska et al., 2018). Given existing racial health inequalities in the NHS and the limited understanding of FND, it may be that individuals belonging to particular ethnic, cultural and faith groups do not access or benefit from mainstream FND services and treatments as a result of, differing understandings and previous experiences of accessing services. Furthermore, cultural upbringing, religious understandings and wider held cultural and health beliefs may influence the experience of their condition.

Aim:

The overarching research aim was to explore whether family/faith/culture play a role in the experience of FND in Black and Asian cultural and faith-based groups. There are four particular aspects of this experience that of interest to the study:

1. How do individuals who have faith and/or are from a Black, Asian or Minority Ethnic cultural background experience their FND?
2. How do individuals with faith and/or a Black, Asian or Minority Ethnic cultural background understand their FND?
3. What is their experience of treatment for their FND (if any)?
4. What are participants’ experiences and responses to their family’s/friends’/closest community’s understanding of their FND?

Method: Semi-structured interviews were carried out with seven individuals. Data were analysed using Interpretative Phenomenological Analysis (IPA) which is concerned with understanding how people make sense of their experiences (Smith et al., 2009).

Results: Three major themes emerged from the data: A cycle of mistrust, navigating the labyrinth and having faith in faith. Each superordinate theme included a set of subthemes which further captured the experiences of individuals. Cultural influences such as help-seeking behaviours, symptom and suffering perceptions, upbringing and language were found to play a part in how one experiences FND. Stigma in perceptions of symptoms from family and friends and health care professionals (HCPs) were found to have a negative impact on individuals’ own perceptions of their difficulties. Existing stigma of FNDs was found to further debilitate individuals and in some cases, meant that participants did not return to

services. Participants reported feeling isolated in their journeys but reported finding strength and hope in faith.

Conclusions: This study provides insights into the experiences of FND in Black and Asian individuals. Stigma and faith were found to play a significant role in individuals' experiences. Recommendations have been made for teaching on FNDs to be provided in clinical training programmes, this in turn can help reduce stigma in HCPs. Additionally, for HCPs to spend time hearing and learning more about the patient's understanding and what they and those around them would find most helpful now. Validating experiences and working with patient understandings is a key step towards therapeutic engagement, patient empowerment and improved outcomes.

Appendix P. Draft research summary to be sent to participants

Study title: ‘With Hardship Comes Ease’: Black and Asian individuals’ experiences of Functional Neurological Disorder

Dear participant,

I would like to thank you for taking part in the study, for giving me your time and sharing your story. The research has now come to an end, as agreed, please see below a summary of the findings.

Background

One in five individuals present to primary care services (e.g. GP or A&E) describing physical symptoms such as non-epileptic seizures, dystonia, limb weakness, walking difficulties, visual impairment, numbness, headaches and paralysis. One way of understanding the collection of these symptoms is under the diagnosis of a functional neurological disorder (FND). Research indicates that individuals and their families can find the diagnosis of FND difficult to understand and the transition from a physical health setting to mental health services challenging (Kozłowska et al., 2018). Given existing racial health inequalities in the NHS and the limited understanding of FND, it may be that individuals belonging to particular ethnic, cultural and faith groups do not access or benefit from mainstream FND services and treatments due to differing understandings of their condition or experiences of accessing services. Cultural upbringing, religious understandings and wider held cultural and health beliefs may influence the experience of their condition. This research provides an opportunity to understand the experiences of Black and Asian individuals experiencing symptoms of FND.

Method

Semi-structured interviews were carried out with seven individuals. Data were analysed using Interpretative Phenomenological Analysis (IPA) which is concerned with understanding how people make sense of their experiences (Smith et al., 2009).

Results

Three major themes emerged from the data: A cycle of mistrust, Navigating the labyrinth and Having faith in faith. Each superordinate theme included a set of subthemes which further captured the experiences of individuals.

A cycle of mistrust

This theme described the role of mistrust and disbelief in participants’ experience and management of the symptoms. Participants had experiences of others’ (friends, family and services) doubting the genuine nature of the symptoms, questioning their understanding and the impact of them. It also captures participants’ experiences of having to ‘prove themselves’ and sometimes finding themselves questioning their own symptoms. Finally, it captures the evolving view of doctors and services, from trust to lack of confidence in services due to several unhelpful interactions and experiences.

Navigating the labyrinth

This theme captured the participants' experiences of navigating the condition and the system (friends, family and healthcare system). Understandings can largely be captured under spiritual interpretations and medical interpretations. Participants reported trying to make sense of their symptoms in a healthcare system where high stigma and limited knowledge of FND exists. As such, participants spoke about becoming self-sufficient by becoming knowledgeable in their own symptoms and conditions, this seemed to help them to advocate for themselves when accessing services. Feelings of isolation arose for many of the participants in their journey because of their needs not being met, not feeling heard or understood, not being able to access the right support or because of stigma. Finally, participants spoke of the complexity coming to terms with living with debilitating symptoms while navigating services as a Black or Asian individual. Being an ethnic minority within a minority system (falling between the cracks of neurology and psychiatry) where both social and cultural stigma and prejudice shaped the participant's experience.

Having faith in faith

This theme captured the significance of faith in many of the participant's lives. Faith provided empowerment and hope in what was a relentless journey for the participants. On a journey of uncertainty, it was clear that the only certainty participants could have faith in, was their faith. Within this, participants spoke of the emotional and sometimes physical healing they found through their faith.

Conclusions

The aim of this study was to understand the role of family, culture and faith in the experience of functional neurological type symptoms. Stigma and faith were found to play a significant role in participants' experiences. Clinical implications included providing teaching on FNDs in clinical training programmes which can reduce stigma in healthcare professionals and providing compassionate person-centred care. Being curious in how culture, socio-political context, and individual histories might influence experiences might also help to increase engagement and reduce distress.

Further dissemination

As specified in the information sheet, I hope to submit this research to a published journal. This will include anonymised quotes to evidence key findings.

I hope these findings have been interesting to you and once again, thank you for your contribution to the study.

Best wishes,

Aysha Baloch

Trainee Clinical Psychologist

Appendix Q. Journal author submission guidelines

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