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ABSTRACT

Research highlights that ethnic minority females are less likely to receive a diagnosis or treatment for an eating disorder (ED). The other half of the therapeutic alliance is therapists, and their role and input should not be understated when aiming for positive outcomes for this group. This research explores therapists perspectives in terms of their experiences; what working with this group means to the therapists themselves; and their experience of working with cultural concepts.

Semi-structured interviews were conducted with 12 therapists in the UK, London and thematic analysis was used to analyse the data. Shame was often cited as a barrier to accessing help. This had different influences on their therapeutic work, such as not questioning shame or linking this to a negative interpretation of parents. There was also the concept that ethnic minorities were more likely to present with emotional and interpersonal factors fuelling the ED, although this conflicted with the notion of the Western body ideal being an influence. Participants also revealed a feeling of being restricted by service management, having a limited time to reflect on cultural issues, and the worry about being offensive or doing something wrong.

Subtle steps can be taken to encourage new and creative ways of addressing the issues highlighted. Services and guidelines should support therapists through regular reflective practice on cultural issues. Hierarchy in teams could be addressed by encouraging diversity in decision making. To break down the perceived barrier of shame, the use of cultural genograms and cultural scripts could be encouraged to understand the ED context. Referral guides could be developed to inform primary care of the warning signs of EDs that may not feature in the diagnostic criteria. Recommendations should aim to balance the nuances of the individual, alongside a systematic rollout to address unmet needs.

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Abbreviations Used Throughout the Thesis

AN = anorexia nervosa

BED = binge eating disorder

BN = bulimia nervosa

CBT = Cognitive Behavioural Therapy

CBT-E = Enhanced Cognitive Behaviour Therapy for eating disorders

EAT = Eating Attitudes Test

ED = eating disorder

EDNOS = eating disorder not otherwise specified

DSM = Diagnostic and Statistical Manual of Mental Disorders

FBT = Family-Based Treatment of Eating Disorders (The Maudsley Method)

FDED = females diagnosed with an eating disorder

FDAN = females diagnosed with anorexia nervosa

FDBN = females diagnosed with bulimia nervosa

GEMM = Good Ethnic Mainstream Minority

GP = General Practitioner

ICD = International Classification of Diseases

NHS = National Health Service

NICE = The National Institute for Health and Care Excellence

PIS = Participant Information Sheet

SEDS = Specialist Eating Disorder Service

SU = Service-User

SWAG = skinny White affluent girls

TA = Thematic Analysis

UEL = University of East London

UK = United Kingdom

For Jessie. Always in my heart

1 INTRODUCTION

1.1 Chapter Overview

In 2014, the Government announced an additional £30m in funding per year to support Specialist Eating Disorder Services (SEDS) across England (National Collaborating Centre for Mental Health, 2015). The initiative was specifically intended to improve early access to treatment and provide national staff training to meet the needs of children and young people diagnosed with eating disorders (EDs). Nevertheless, a systematic review by Sinha and Warfa (2013) suggests that people from ethnic minority backgrounds are less likely to be diagnosed with an ED and therefore, to be referred to receive treatment. Such inequalities must be addressed since EDs significantly impact a person's psychological and physical well-being in terms of high mortality rates and ominous long term outcomes (Fichter & Quadflieg, 2016; Fichter, Quadflieg, Crosby, & Koch, 2017; Quadflieg & Fichter, 2019).

This thesis aims to explore areas that require attention in the identification and treatment of ethnic minority females diagnosed with EDs in the United Kingdom (UK). This will be achieved by providing an insight into ethnic minority females diagnosed with EDs, through the perspectives of the therapists who work with them, in terms of their experiences; what working with this group means to the therapists themselves; and their experience of working with cultural concepts. The rationale for exploring therapists perspectives is that this group are part of what determines whether ethnic minority females diagnosed with EDs receive treatment and the quality of care they receive. This perspective has not been or has only been tangentially researched before - with the majority of previous studies being centred around the perspective of service users (SU).

This Introduction chapter provides a more detailed discussion as to the rationale for this thesis and the approach. The chapter begins by defining what EDs are and why the associated physical and psychological need deems this research valuable. The limitations of the recommended theoretical models are explored, and the typical patient care pathway, when applied to ethnic minority females diagnosed with EDs, is

explained. The chapter will subsequently provide a scoping review of empirical studies that have conducted work as follows:

- 1) Research of a therapist's perspective of ethnic minority females diagnosed with EDs in the UK.
- Research into ethnic minority females diagnosed with EDs in the UK.
 At present, there is limited research into the therapist's experience of working with

ethnic minority females diagnosed with EDs, and this question forms the foundation of this thesis.

1.2 Eating Disorders Defined

1.2.1 <u>Terminology</u>

1.2.1.1 Eating disorders

The term "ED" will be used as in the UK a formal diagnosis is typically required by SEDS for individuals to be offered treatment and is therefore frequently used by professionals working within these services. From a critical realist epistemological stance, the professional representation of an ED diagnosis as a discrete and universal condition is viewed critically. Furthermore, it is acknowledged that the theories used to generate this terminology are socially constructed (Bentall & Pilgrim, 1999). The Eurocentric standpoint used to generate diagnostic terms may be unhelpful when applied to other cultures (Ratan, Gandhi, & Palmer, 1998). As such, when referring to women and girls, the term "females diagnosed with EDs" (FDED) is used, since the ED diagnosis is not integral to the person.

Lastly, EDs typically require the physical health complications of malnutrition to be addressed alongside providing psychological therapy. In this thesis addressing the psychological aspects will be referred to as "therapy". Typically therapists, who include psychologists and family therapists, provide therapy and are also involved in ensuring that the physical health complications are addressed by medical professionals. The word "treatment" is used to address this combined role of therapists.

1.2.1.2 Race, ethnicity and culture

The following section will discuss the terms, race, culture and ethnicity, insofar as they are relevant for this thesis. The term race has been argued to refer to a sociopolitical construction whereby people are assigned to demographic or 'biological' categories based on their skin colour, genetics, or the hair type of their ancestors or themselves (Helms, Jernigan, & Mascher, 2005). The concept of race has been largely discredited. Nevertheless, the impact of this socially constructed category is real and felt through racism (Donald & Rattansi, 1992). Along with racial categories, comes racial hierarchies whereby race infers a status or class. This is most prominently depicted by what Chatterjee (1994) calls the 'rule of colonial difference' whereby the colonised are seen to be inferior to the colonisers (Chatterjee, 1994). Such ideologies underpinned, for example, British colonial rule in South Asia and parts of Africa. Proximity to 'Whiteness' was seen as desirable and thereby justified the racism experienced by those from racialised minority groups (Chatterjee, 1994).

Race is considered to be visible in the form of skin colour or physical features and this allows a reductionist interpretation to people of colour, and perhaps leads to inequality (Gunaratnam, 2003). The term ethnicity is a broader construct than race. It refers to a subjective definition of oneself concerning several factors including food, geography religion, language and skin colour, including others (Bhopal, 2014; Jandt, 2017). Furthermore, culture refers to a groups patterns of behaviour, thoughts and values about what is deemed good or bad (Jandt, 2017). Specifically, it defines a social framework of norms, rituals, language, expectations, values, taboos and rules (Triandis, 1996). It is argued that it is not necessarily a preference or something that is chosen. This term also includes a wider context, that is inequality or power that is inherent to that culture (Donald & Rattansi, 1992).

The present research and literature review focuses on ethnic minority categories in the UK, which are based on people of a similar heritage or culture, who do not identify as White: South and East Asian, Asian British, Black, African, Caribbean, Black British, Mixed or Multiple ethnic groups, Arab or other non-White minority ethnic groups. These categories are not perfect since in the UK these categories are still largely based on race and demographics and there is heterogeneity within each ethnic category. Furthermore, the term ethnic minority is used over the term "BAME"

(Black and Asian minority ethnic) so as not to homogenise ethnic minority groups under one label. It is recognised that this terminology is also imperfect, although allows for ease of communication in this thesis.

1.2.2 Diagnostic Classifications

The diagnostic classifications and criteria are detailed in this section, to provide a reference point for the reader in the later sections which explore how ethnic minority FDEDs present and in what ways they differ. According to the 11th edition of the International Classification of Diseases and Related Health Problems (ICD-11), feeding and EDs include anorexia nervosa (AN), bulimia nervosa (BN) and binge eating disorder (BED), pica, avoidant restrictive food intake disorders and rumination-regurgitation disorder (World Health Organization, 2019). Diagnosis is applied using diagnostic criteria and clinical judgement based on the National Institute of Clinical Excellence (NICE) guidance (NICE, 2017; World Health Organization, 2019). The most common EDs are AN and BN. The guidelines propose that essential features for a diagnosis of AN include:

- (1) Significantly low body weight, such as a body mass index (BMI) of below 18.5 kg/m2.
- (2) A persistent pattern to reduce energy intake and related behaviours.
- (3) Low weight is overvalued, and there is a preoccupation with shape.

A diagnosis of BN requires the following essential features:

- (1) Recurrent episodes of binge eating.
- (2) Repeated inappropriate compensatory behaviours to prevent weight gain, such as vomiting.
- (3) Distress associated with bingeing and compensatory behaviours.
- (4) Excessive preoccupation with weight and shape.
- (5) The individual does not fit the criteria for AN.

1.2.2.1 Limitations of diagnostic classifications and alternatives Diagnostic categories have purpose and usefulness within an NHS multidisciplinary team and in academic settings. They facilitate the ease of information sharing and understanding within services (Thomas et al., 2010). Nevertheless, diagnostic categories are socially constructed, based on clinical descriptions as opposed to

objective characteristics (Johnstone & Boyle, 2018). As such diagnostic categories have changed over time, across cultures and social settings (Gergen, 1985).

Arguably past research has been limited by overreliance on diagnostic criteria. This presents as problematic since diagnostic categories have mainly been developed based on American and Northern European data. As such, it reduces exploration of unrecognised cultural diversity which may exist outside of those categories (Becker, 2007). Furthermore, DSM-5 diagnostic categories may exclude those with subclinical symptoms, yet are experiencing psychological distress. This is important to note since a diagnosis is needed to receive treatment for an ED.

In a practical setting, these labels can reductively attribute the cause of psychological distress to the individual, thereby ignoring the broader contextual factors which contribute to their experience (Bentall & Pilgrim, 1999). Furthermore, for the person experiencing psychological distress, the meaning behind these features and how it relates to their cultural narrative might differ (Channa et al., 2019). The different meanings behind the labels are perhaps most notably demonstrated by the moderate inter-rater reliability rates for eating disorder diagnoses (κ =.57) and poor inter-rater reliability rates for other specified feeding or eating disorder (OSFED) (κ =.05) (Thomas et al., 2015).

Alternatives to diagnostic categories include psychological formulation. This process allows a person's distress to be understood within the context of their relationships, life events and social factors (Johnstone & Dallos, 2013).

1.2.3 Epidemiology

It is crucial to gain an overview of the prevalence of EDs across ethnic groups. This is because the numbers of ethnic minorities obtaining help from SEDs is relatively low, leading to the misconception that ethnic minorities are less likely to suffer from EDs (Waller et al., 2009). Prevalence estimates in this section will focus on females since this is the focus of this research. Females have been chosen as the focus since both men and ethnic minorities are marginalised groups in the field of ED research and practice (Joint Commissioning Panel for Mental Health, 2014). This approach will

ensure enough literature for interpretation since the data on men who are diagnosed with EDs and of ethnic minority background is minimal. Furthermore, the 'intersectionality' that exists by the interaction of gender and race creates another layer of interpretation (Crenshaw, 1989).

There have been limited studies of the prevalence of EDs in culturally diverse populations (Becker, 2007). In the UK, studies of prevalence by ethnicity suffer from a limited sample size (N=145) (Solmi, Hatch, Hotopf, Treasure, & Micali, 2014). A longitudinal community-based UK sample of women showed that the 12-month prevalence of EDs was 3.6%, and by midlife, the lifetime prevalence was 15.3% (Micali et al., 2017). The most common lifetime EDs were AN, affecting 3.6% of women in their lifetime and OSFED (other specified eating disorder) (7.6%) (Micali et al., 2017).

In the US, the prevalence of EDs (n=1777 across 36 months) did not differ significantly between ethnic groups (found (χ 2 [3,1177] = 0.23, p = .97). The specific prevalence rates were as follows; 19.8% White, 19.9% Hispanic American, 20.7% African American, and 21.5% Asian American (Cheng, Perko, Fuller-Marashi, Gau, & Stice, 2019). Since diagnostic criteria have been validated largely in White samples, any study of prevalence potentially underestimates occurrences in ethnic minorities since it largely excludes those who do not fit with the ICD-11 or fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria (American Psychiatric Association, 2013; World Health Organization, 2019).

1.2.4 Long-Term Outcome

Long-term outcomes are ominous, and, generally, earlier intervention is associated with better treatment outcomes (Brown et al., 2018). A UK report has indicated that timely treatment of EDs is necessary since the long-term course is poor, meaning the cost to individuals, families and the economy is high (Price Waterhouse Coopers commissioned by BEAT, 2015). At follow-up over 25 years, only 30% of 1693 females sufficiently improved so that a diagnosis of AN was no longer applicable (Fichter et al., 2017). For BN, at follow-up over 11 years, 38% out of a sample of 2033 improved so that a diagnosis was no longer applicable (Quadflieg & Fichter, 2019). Mortality rates are also high. The standardised mortality ratio is 1.49 in BN and 5.38 in AN, with

individuals mostly dying of causes due to the physical complications associated with EDs (Fichter & Quadflieg, 2016). Given these poor outcomes, people presenting with ED features must be recognised and addressed as soon as possible.

1.3 Theoretical Models Of Eating Disorders

1.3.1 Biopsychosocial Perspective

The biopsychosocial perspective goes on the assumption that EDs arise as a combination of biological, social and psychological factors (Engel, 1977). The cognitive-interpersonal model of AN is based on these assumptions and incorporates both intra and interpersonal factors (Schmidt & Treasure, 2006). This model proposes that AN involves inherited vulnerabilities such as behavioural inflexibility, difficulties in seeing the bigger picture and in social and emotional processing (Treasure & Schmidt, 2013). The model concerns the physical consequences of starvation on the brain and alterations to the microbiome and suggests that the metabolic and endocrine system may exacerbate the aforementioned factors and therefore serve to maintain the AN (Himmerich, Bentley, Kan, & Treasure, 2019; Schmidt & Treasure, 2006). Other maintenance factors include experiential avoidance, pro-anorexic beliefs and perfectionism. Environmental factors such as the response of close others and families with high expressed emotion may maintain the AN. Reactions to the frightening physical deterioration may include criticism, hostility and over-protection, which serve to maintain and enable AN (Schmidt & Treasure, 2006).

1.3.2 Socio-Cultural Perspective

The socio-cultural perspective of EDs proposes that exposure to Western ideals of thinness are internalised, which leads to body dissatisfaction and risk to ED development. The most well-known is the dual pathway model (Stice & Menke, 2015). In this model, it is proposed that pressures from society, family and peers favour a thin ideal and this ideal becomes internalised as the individuals own preference for body image. Also, the dietary restraint model and the affect regulation model are included to explain the development and maintenance of BN (Stice & Menke, 2015). Another socio-cultural model is the tripartite model which goes further and incorporates three pathways that lead to EDs. These include 1) perceptions of health and wellness, 2)

ideal body weight and shape and 3) eating behaviours that have been passed down from previous generations (Markey, 2004).

Keel and Klump (2003) observed that ED presentations were dependent on the accessibility of food in society. For BN, the relatively recent socio-cultural changes in weight concern, desire for thinness and increase in palatable foods were thought to explain the increase in prevalence from the 19th to the 20th century (Habermas, 1989). However, others do provide evidence of BN occurring in non-western developing countries such as Pakistan and China, in the early nineties, before the more recent Westernisation of these countries (Lee, Hsu, & Wing, 1992; Mumford, Whitehouse, & Choudry, 1992). Urban areas have also been associated with an increased risk of BN, although not AN (Van Son, Van Hoeken, Bartelds, Van Furth, & Hoek, 2006). According to Keel and Klump (2003), excessive concern with weight and shape (which is one of the diagnostic criteria for AN) appears to be a recent phenomenon associated with Western culture and influence (Keel & Klump, 2003). However, refusal to eat and resulting emaciation appears to have occurred across cultures and is documented historically (Keel & Klump, 2003).

1.4 Access And Treatment Of Eating Disorders

1.4.1 Accessing Specialist Eating Disorders Services

EDs can be recognised in several settings including, home, school, work, social care and primary and secondary health care (NICE, 2017). At some services, self-referral is allowed. However, more often, a referral to SEDs needs to occur through a general practitioner (GP) or other primary or secondary care health professional. Once referred to a SEDS, the person and their caregivers are assessed typically by a group of staff from multiple disciplines that may include psychologists, family therapists, doctors, nurses, psychiatrists or dietitians. The decision to offer treatment is based on clinical judgement of several factors relating to the ED, such as weight and shape concerns and physical signs of malnutrition. Alongside this, quantifiable measures, including the Eating Disorder Examination Questionnaire (EDE-Q), are often used to assess the severity of the ED (Fairburn & Beglin, 2008).

1.4.2 NICE Guidance Recommended Treatment For Adults And Adolescents

NICE, which is a national institute, provides guidelines for evidence-based health and care based on the recommendations of an independent committee. Somewhat conflicting with the aforementioned Eurocentric approach to research and treatment of EDs in the UK, the guidelines for EDs emphasise the importance of incorporating service-users (SU) values, preferences, and characteristics such as culture and ethnicity (NICE, 2017). The guidelines state the following:

"Ensure that all people with an ED and their parents or carers (as appropriate) have equal access to treatments (including through self-referral) for EDs, regardless of: age, gender or gender identity (including people who are transgender) sexual orientation, socioeconomic status, religion, belief, culture, family origin or ethnicity where they live and who they live with and any physical or other mental health problems or disabilities (p.41) (NICE, 2017)".

In practice, treatment of EDs involves a combination of medical monitoring (due to the significant physical medical complications), dietetics support with weight stabilisation, psychoeducation and psychological therapy (NICE, 2017). The primary therapies offered include Family-Based Treatment of Eating Disorders - The Maudsley Method (FBT) and the Enhanced Cognitive Behaviour Therapy for eating disorders (CBT-E) for young people and adults (Eisler, Simic, Blessitt, & Dodge, 2016; Fairburn, 2008). FBT focuses on emphasising the family's role in helping the person manage their eating. The model does not focus on blame or what caused the ED (Eisler, Simic, Blessitt, et al., 2016). CBT-E begins by gaining a mutual understanding of the ED through formulation and psychoeducation and encouraging regular eating. It later focuses on what may be maintaining the ED in terms of weight and shape concern and emotions (Fairburn, 2008). Whether social or cultural nuances are incorporated into treatment is dependent on the therapist and the SU. Greater recognition of the diversity in features might improve culturally competent care of EDs (Franko, Becker, Thomas, & Herzog, 2007).

1.5 Limitations Of The Current Models, Access And Treatment

1.5.1 The Marginalisation Of Ethnic Minorities In Eating Disorders

One of the aims of this thesis is to address the growing acknowledgement from commissioning groups that effort should be made to reduce low utilisation of mental health services by ethnic minorities (Joint Commissioning Panel for Mental Health, 2014). The report expressly referred to the development of culturally capable mental health services. Such services should be personalised to the cultural and ethnic backgrounds of SUs to improve outcomes (Joint Commissioning Panel for Mental Health, 2014).

A review of 12 studies (2 UK and 10 US) has shown that ethnic minorities are less likely to be diagnosed with an ED and be referred for or receive treatment for an ED (Sinha & Warfa, 2013). A vicious cycle has perhaps occurred, whereby ethnic minorities in the UK have been marginalised in the research of EDs which in turn contributed to a lack of awareness of how these conditions presented in ethnic minorities and cultivated the skinny White affluent girl (SWAG) stereotype (Sonneville & Lipson, 2018). The marginalisation of ethnic minorities has hindered the development of theoretical and therapeutic models which address the needs of the full spectrum of EDs (Becker, 2007). Indeed these models can be reductionist in their focus on eating behaviours and in addressing weight and shape concerns while failing to recognise the social conditions in which psychological distress arises (Bentall & Pilgrim, 1999). Therefore at referral, therapists and GPs fail to consistently recognise uncommon presentations of EDs which fall outside the range of the ICD-10 criteria (Waller et al., 2009; World Health Organization, 2019). Reduced recognition, further alienates ethnic minorities from seeking help and maintains the belief that ED presentation is homogenous.

1.5.2 Service-Users Versus A Therapists Perspective Of The Problem

Most empirical studies in the field of EDs have been conducted on SUs. These studies have primarily been designed by academics and therapists who investigate the "patients" presentation or perspective. These studies are mostly designed based on Eurocentric, reductionist and theoretical perspectives and assumptions. Although these studies propose to investigate the SUs perspective, they also inevitably reveal

the researcher's or therapist's perspective. Significantly less research has directly approached the study of therapists' perspectives on working with EDs. Such findings might provide a broader understanding of the theoretical perspectives that construct the understanding of ethnic minority FDEDs. This perspective is essential since therapists are part of what determines whether ethnic minority FDEDs receive treatment and the quality of care they receive.

From the critical realist epistemological position, it is proposed that no perspective of reality is correct or universal (Bhaskar & Danermark, 2006) and that independent reality is beyond what can be measured or observed (Sayer, 1999). From such a position, one might highlight the importance of gaining perspectives not just from SUs, but also the professionals involved in their therapeutic care. In EDs, the therapists and SUs may uphold different and similar theories with which they construct their perspective on reality. What is defined as an ED by a therapist influences what interventions the therapist provides and also the way the SU understands the ED (Bergin, Wells, & Owen, 2008; Payne, 2006).

Arguably, therapists cannot produce accounts of EDs without referring to SUs' accounts of the psychological distress experienced. Service users may oppose the views of professionals while also accepting and in part, internalising therapists discourses around EDs (Bentall & Pilgrim, 1999; De Swaan, 1990). Importantly there is an interaction between therapists' and SUs' perspectives of EDs.

According to Bentall and Pilgrim (1999), diagnostic labels such as AN, BN or ED, exist in both the SU and professional domains and shared use of these terms sustains culturally specific representations of EDs. Nevertheless, more often (but not always) when therapists or professionals use the term ED in a clinical setting, it is argued to refer to a universal representation. Whereas the SU's use of the term ED is more likely to refer to a subjective and unique experience (Bentall & Pilgrim, 1999). Therefore when studying mental health problems, it is necessary to understand the interplay between the social institutions; and peoples' construction of mental health problems (Bergin et al., 2008; Danermark, Ekström, & Karlsson, 2019).

Therapists hold a unique perspective which is influenced by many strata (Bhaskar, 1978). They hold professional knowledge of SEDS, guidelines for treatment by NICE (2017), the ICD-11 diagnostic criteria and treatment models (World Health Organization, 2019). They may also have experiences of EDs in their personal life. They also hold knowledge of the SUs that they have worked with (which includes how they present) and the personal experience of providing therapy for them.

1.6 Literature Review Method

Research that explores therapists' perspectives on working with ethnic minority FDEDs in the UK has the potential to improve access and treatment for this group. It was decided that the literature review should focus on prior research of a therapist's perspective of ethnic minority FDEDs in the UK, and this is provided in section 1.7. Given the apparent paucity of this research, it was considered necessary to widen the scope of the review. The approach of focusing on the more extensive literature which explores therapists experiences of working with other forms of psychological distress such as 'psychosis' or 'depression' was rejected and deemed beyond the scope of this review - since such findings are likely to be unique to that group and setting, and have less relevance to the interpretation of the present research findings. As such, it was decided that the remainder of the literature review would focus on prior research concerning ethnic minority FDEDs in the UK, provided in section 1.8. This is vital since it was felt that such research might indirectly provide the reader with some insight into the context and formation of therapists perspectives which are discussed in the Results (section 3) and Discussion (section 4). Furthermore, this review will provide a reference point to the reader for the therapists perspectives that are discussed.

1.6.1 Search Strategy

A scoping review strategy was conducted to identify key concepts and gaps in the literature. Four databases were searched, namely: Psychinfo, Psycharticles, Academic Search Complete and Science Direct. Google scholar and other platforms were used to search literature outside of these databases. The following search terms

were used: Ethnic minorit*1 OR Race OR Cultur* AND ED* OR bulimia nervosa OR anorexia nervosa OR binge eating disorder. Studies were excluded if they were about "disordered eating" that did not meet the full diagnostic criteria, if they concerned men, or, were not conducted in the UK. Papers on disordered eating were excluded since therapists are less likely to have provided therapy to people presenting with this since therapy at SEDS is typically provided based on having been diagnosed with an ED as defined by ICD-11 (World Health Organization, 2019).

Papers were included if they were about ethnic minority FDEDs or therapists' perceptions of ethnic minority FDEDs, conducted anytime, no comparator group was required and involved an empirical study and the paper was written in English (see Figure 1).

¹ * is a Boolean operator which services as a truncation. Therefore search terms will match if they begin with the word preceding the * operator.

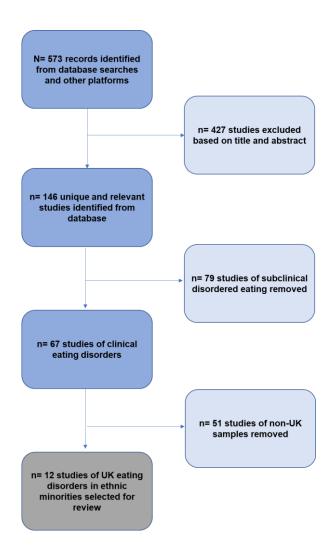


Figure 1: Flowchart of papers included

1.6.2 Papers Selected For Review

The review (outlined in section 1.6.1) only found two papers which tangentially explored a therapists perspective of ethnic minority FDEDs in the UK and this is discussed in section 1.7. The broader scoping review of ethnic minority FDEDs in the UK obtained an additional ten papers, and these are discussed in greater detail in section 1.8. A summary table of the 12 papers obtained is provided in Appendix 1.

The literature on ethnic minority FDEDs in the UK is grossly limited. Therefore, to provide the reader with a broader understanding of ethnic minority FDEDs and therapists perspectives of ethnic minority FDEDs, sections 1.7 and 1.8 also includes ancillary literature of representative samples in the UK and studies outside of the UK,

such as in the US. These papers were of specific interest to the present research and were obtained from the initial search (section 1.6.1) although they did not meet full criteria to be included in the final review.

1.7 Literature Review I: Research Of A Therapists Perspective of Ethnic Minority Females Diagnosed With Eating Disorders In The UK

1.7.1 Summary Of Studies

The scoping review did not find any studies which directly explored a therapists' experience of working with ethnic minority FDEDs in the UK. However, two studies have tangentially explored therapists' and health professionals' perceptions of British ethnic minority FDEDs. The first was conducted in Leicester, England (Wales, Brewin, Raghavan, & Arcelus, 2017) and investigated South Asians from the local community (n=28) and therapists (n=16) working with South Asian FDEDs using focus group methodology. Importantly this study conducted a thematic analysis of the data of South Asians and therapists combined; therefore, it is not possible to draw direct conclusions about therapists' perceptions solely from this study. Furthermore, the study did not enquire into or interpret therapists experience of working with South Asian FDEDs, merely used their reports as key informants.

The sample (which included, therapists and a community sample of South Asians) perceived stigma and shame to have implications for the success of treatment and often caused a delay in presentation to services. There were reports that South Asians were more likely to cite physical illnesses as their primary problem. They queried whether this was due to reduced awareness or lack of appropriate language to describe what they were experiencing. The former suggestion is perhaps questionable. It may also be argued that therapists inappropriately apply Western derived theoretical models of EDs due to a reduced awareness of how EDs present in ethnic minorities. Nevertheless, therapists reported that improved awareness could be achieved by ED service leaflets that emphasise how to seek help and confidentiality at the point of contact (Wales et al., 2017).

The second study by Chowbey and colleagues (2012) was a community based qualitative study in Sheffield, England. It involved Pakistani, Bangladeshi, Somali,

Yemeni and Indian people. The study interviewed carers of those with EDs (n=3) and key informants who work with people diagnosed with EDs (n=15) and completed focus group discussions with a representative sample of young (aged 18 to 24) ethnic minorities (n=24). The thematic analysis integrated reports from carers, young people and key informants. Integration presents a methodological issue since the perspectives of these groups arise from differing standpoints.

Key informants expressed a desire to meet the needs of ethnic minorities but that they were unsure how exactly as they had not had specific training in this area (Chowbey, Salway, & Ismail, 2012). At present specific guidance on the issues raised in this study does not exist in the NICE guidelines and the recommended treatment models. A lack of guidance perhaps leaves therapists who are motivated to improve their work with ethnic minorities, with little evidence-based information on how to do so.

In the ancillary literature, there is a US study of 11 therapists experiences of working with Asian American FDEDs (Smart, Tsong, Mejía, Hayashino, & Braaten, 2011). The study explored Asian American FDEDs through the perspective of their therapists and how the therapists report approaching therapy with this group. Therapists identified culturally specific factors that they had observed in Asian American FDEDs, which included the desire to achieve in the areas of academics, career and appearance at all costs (Smart et al., 2011). Nevertheless it is noted that perfectionistic tendencies are common with EDs and may not be linked to the ethnicity of this group (Obeid et al., 2020).

Questions about each therapist's approach to treatment indicated they had adapted their style to better suit Asian American culture (Smart et al., 2011). This was achieved by providing psychoeducation, addressing emotions and perfectionism and normalising therapy to reduce shame and the risk of drop-out. This also functioned to challenge Asian norms about beauty standards. The therapists explained that they needed to adapt to work with different family dynamics since parents often did not comply with the therapy programme or did not return to sessions (Smart et al., 2011). Indeed, aforementioned research has indicated that therapists reported having to educate the parents about the ED and the importance of family engagement (Wales et al., 2017).

It may be argued that this approach of 'educating' ethnic minority parents about conditions defined by Eurocentric and Western theoretical models is one-sided. Unfortunately, there was no reference to therapists learning about the cultural frameworks that parents used to help their child with the ED (Smart et al., 2011). It is acknowledged that a shared understanding between both therapists and SUs is needed for therapy to be successful. A good therapeutic alliance and a rapport should be established before exploring sensitive factors such as culture in treatment (Beck, 2019).

Holmes (2018) explored the views of 12 UK health professionals regarding whether socio-cultural perspectives were valued and explored in ED treatment. Although this study was not specifically about working with ethnic minority FDEDs, it did reveal that cultural risk factors were inconsistently incorporated by health professionals into assessment and treatment. Some of the therapists stated that they had 'never really considered' including cultural constructions into treatment. The study concluded that socio-cultural factors were often ignored in treatment due to the current climate of emphases on the biopsychosocial framework underpinning evidence-based treatment in the UK (Holmes, 2018).

1.7.2 Concluding Summary

In conclusion, Literature Review I, found only two papers that tangentially explored therapists' experiences of working with British ethnic minority FDEDs in Leicester and Sheffield (Chowbey et al., 2012; Wales et al., 2017). In summary, both suffered from methodological issues, in that the analysis combined the reports by therapists with SUs and carers. Furthermore, the focus of the research was largely (but not exclusively) on the SUs presentations, as opposed exploring therapists views. However, one relevant finding for this research is that therapists reported a lack of specific training in working with ethnic minorities and a desire to meet their needs (Chowbey et al., 2012).

1.8 Literature Review II: Research Of Ethnic Minorities Diagnosed With Eating Disorders In The UK

1.8.1 Eating Disorder Presentation

Individual eating behaviours are impacted by cultural expectations that arise from ecological systems such as societal standards, family and peers (Markey Hood, Vander Wal, & Gibbons, 2009). Consequently, ethnic minority FDEDs may present with behaviours and emotions that fall outside the range of theoretical models of EDs (section 1.3) and diagnostic criteria (section 1.2.2). The discrepancy occurs since these models have been primarily developed from a Eurocentric and reductionist perspective. The DSM has attempted to address cultural nuances via the section 'Culture-Related Diagnostic Issues'. Here, it is noted that some ethnic minority females may present differently (American Psychiatric Association, 2013). It explains that the SU may express gastrointestinal discomfort or loss of appetite, which are more culturally sanctioned in Asia (American Psychiatric Association, 2013). It also stated that intense fear of weight gain might be absent in Asian populations. However, to date, no formal guidance on this has been included. Indeed this section is presented after the main diagnostic criteria for EDs and therefore easily overlooked (American Psychiatric Association, 2013).

There is evidence to support the issues raised in the section of the DSM on culture. A small case note study of 14 British South Asian adolescent females with weight loss or displaying features of AN, showed that in comparison to their White peers, they presented more frequently with loss of appetite and less frequently with a phobia of fatness and weight preoccupation (Tareen, Hodes, & Rangel, 2005). Similarly, an observational study of British Asian females diagnosed with AN (FDAN) from a 34-year database showed that this group were less likely to acknowledge sensitivity to fatness at the start of treatment although this changed during treatment with weight gain (Soomro, Crisp, Lynch, Tran, & Joughin, 1995).

Regarding BN, there have been mixed findings. One study found that ethnic minorities (55.4%) were more likely than their White counterparts (33.6%) to receive a diagnosis of BN (Waller et al., 2009). However, this could reflect a referral bias, with referrers considering those displaying overt behavioural features of BN, such as vomiting and

bingeing, as more likely to need specialist care (Waller et al., 2009). Another study of referrals presenting to a SEDS in Leicester across 15 years indicated that the features of BN and eating disorder not otherwise specified (EDNOS) were similar between Asians and other ethnic groups including White, but that the Asian group were younger (Abbas et al., 2010). The features of comparison included self-induced vomiting, laxative abuse, binge eating, guilt and disgust about weight and eating. The presence of these features is perhaps not unexpected, given that SUs would need to fulfil SEDS criteria to be seen for treatment. Indeed, this further demonstrates how the evidence base may not be fully representative of ethnic minorities in the community. It is also noted that the study could not assess AN since the sample size was too small (n=4) (Abbas et al., 2010). It is suggested that AN differs between Asian and White females with the former being more likely to present with non-fat phobia (Tareen et al., 2005).

A study in South West London suggested that ethnic minority FDEDs presented with more significant experiences of trauma. This small study compared five British Black and Asian females diagnosed with bulimia nervosa (FDBN) to White FDBN (Lacey & Dolan, 1988). The authors concluded that ethnic minorities had suffered severe emotional deprivation and trauma, including abuse, rape, and being in care. It was observed that ethnic minority FDBN who were referred were less likely to have mild features, in comparison to the majority of referrals which were for mild cases of White FDBN displaying 'less disturbed, uni-impulsive' (p.78) behaviours (Lacey & Dolan, 1988). The disparity may again demonstrate a bias in the referral procedure. Ethnic minority females may need to reach a higher clinical threshold to be considered appropriate for SEDS and therefore are under-represented in such services (Waller et al., 2009).

1.8.2 Familial Factors

The topic of families of FDEDs is vital since the NICE guidance recommended therapies refer to providing family therapy and using families to support the person diagnosed with the ED (NICE, 2017). Family context involves traditions around food, past experiences and habits. All of these can influence eating behaviours (Markey, 2004). This environment can generate associations between food thoughts, behaviours and emotions. Family variables are not considered to be an independent

risk factor, more that they interact with other risk factors such as peer relations and media influences on body ideals (Channa et al., 2019). One study which interviewed family members of ethnic minority FDEDs in Sheffield found reports of a generational gap between children and parents. The FDEDs noted that family pressure to maintain traditional cultural values conflicted with their peer relationships. Parents also felt misunderstood and undervalued by their children. The authors explained that this generational gap impacted getting help early on for the ED. Moreover, they acknowledged that this gap occurred with White parents and children, yet was amplified in this group, due to language and education differences between the parent and child (Chowbey et al., 2012).

Ethnic minority carers of those diagnosed EDs also cite familial shame as a reason for not wanting to seek help (Chowbey et al., 2012). They also cite avoiding their extended family for fear of comments or criticism about the ED (Chowbey et al., 2012). A case study of one British Indian woman diagnosed with BN found that in her family and community, psychological issues were associated with shame and ridicule. As a result, she felt unable to speak to her family about her emotional distress. Furthermore, families surrounding the ethnic minority FDED may uphold thinness ideals. The study explained how she had internalised the thoughts her family emphasised, namely that women should have a certain weight and physical appearance to be considered a viable match for a groom (Channa et al., 2019).

Similarly, a study of South Asian FDEDs presenting to a SEDS in Leicester explained that there was a theme of differing views on relationships between parents and children, specifically concerning marriage (Ratan et al., 1998). On the contrary, it has been hypothesised that the closeness of family networks in South Asian communities may play a protective role (Abbas, 2010). The authors theorised that this might partly explain the lower prevalence of AN in South Asians seen in their 15-year longitudinal study of SEDS referrals in Leicester. Additionally, one study of British South Asians diagnosed with non-fat phobia indicated that they were significantly more likely to report positive relations with their immediate family and close friends (Tareen et al., 2005). Indeed reduced utilisation in ethnic minorities due to family and community support has been acknowledged across mental health services (Bignall, Jeraj, Helsby, & Butt, 2019).

In the ancillary literature, in the US, ED therapists investigated expressed emotion in both White (parents, n=64) and ethnic minority (US-based, Hispanic, Black American or biracial) parents (n=20, parents) of adolescences with BN (Hoste & le Grange, 2008). Expressed emotion was assessed by trained assessors while participants responded to the Standardised Clinical Family Interview (Hoste & le Grange, 2008; Kinston & Loader, 1984). The results indicated no significant differences in expressed emotion between groups. However, the authors noted the trends in the data, which indicated that ethnic minority parents made more critical comments and expressed less positive remarks and warmth than White parents (Hoste & le Grange, 2008). It is important to note that interpreting persons from a different culture is known to reduce the accuracy of emotion recognition and potentially skew the study's findings (Wickline, Bailey, & Nowicki, 2009).

1.8.3 Culture

Acculturation may play a role in increasing the psychological distress that fuels ED features displayed by ethnic minorities. Cultural transition can occur in two ways, the first being the observation of cultures, through urbanisation and industrialisation. The second is through immigration, where there is an acute transition in cultures (Markey Hood et al., 2009). Anderson-Fye and Becker (2004) have defined western culture as cultural values attributable to Western Europe and the United States, and characteristic of dominant North American culture (Anderson-Fye & Becker, 2004).

In Sheffield UK, a focus group of ethnic minorities reported that some felt significant pressure to maintain traditional cultural values and this conflicted with values they experienced outside of the home, at school or with peers (Chowbey et al., 2012). Indeed, another study indicated that in British Asian girls, a high Eating Attitudes Test (EAT) and Body Shape Questionnaire (BSQ) score were associated with a more traditional cultural orientation (Cooper, Taylor, Cooper, & Fairbum, 1987; Garner, Olmsted, Bohr, & Garfinkel, 1982; Mumford, Whitehouse, & Platts, 1991). This entailed language spoken at home and dress.

Another UK case study of four British Asian children diagnosed with AN suggested that cultural conflict was a contributory factor. It is argued that for these second-generation children, there was a cultural conflict between the Western society outside of the home (which may encourage thinness in the context of food which is plentiful) and the traditional cultural values of their parents at home (Bryant-Waugh & Lask, 1991). It was proposed that traditional values for these British Asian children include norms around the style of dress, food, arranged marriages and the role of females in the context of their families. AN has been hypothesised to occur in adolescence due to the conflict between the demand for individuation and dependence which could be heightened in the context of acculturation (Bryant-Waugh & Lask, 1991; Crisp, 1995).

Similarly, authors who studied a 34-year database of White and ethnic minority females hypothesised that during adolescence there is both a shift towards independence and a cultural conflict potentially experienced, the AN then served to re-enmesh the person back with their families (Soomro et al., 1995). Nevertheless, the possibility of AN disrupting adolescent development and creating dependence on families is not specific to ethnic minority FDEDs and is known to occur across ethnic groups (Medway et al., 2019).

In the ancillary literature, a systematic review of studies (N=25) (including those in the UK) found mixed findings over whether ED features were triggered by assimilation to Western culture. Eleven studies supported the association between acculturation and the development of ED features. However, both greater and lesser acculturation was reported as associated with EDs (Doris et al., 2015).

1.8.4 Referral

Overall, studies have concluded that ethnic minority FDEDs are under-represented in services due to low referral rates. One study proposed that the low number of South Asians presenting to SEDS is due to the lack of identification at the primary care level (Waller et al., 2009). Lack of attunement to culturally diverse features may result in cases being misclassified at referral (Becker, 2007). For example, BMI has been normed on Western populations and therefore is invalid when applied to other ethnic groups of FDEDs (Kim et al., 2005). Furthermore, given society's misconception of the

homogeneity of EDs, ethnic minority SUs may assume that the SEDs are not relevant for them (Waller et al., 2009).

A catchment area study of South London showed that ethnic minorities were substantially under-represented in SEDs in proportion to the demographics of the local area, in comparison to their White counterparts (Table 1). Of a cohort of 648 people diagnosed with EDs, White SUs were over-represented by 25%, and Black SUs were underrepresented by 70% in proportion to the demographic of the local area (Waller et al., 2009).

Table 1: Prevalence of ethnic groups diagnosed with EDs in proportion to the demographic of the local catchment area of South London

	Clinical sample (N=648),	Catchment area
	N (%)	population (%)
White	569 (87.8%)	70%
Black	37 (5.7%)	19%
South Asian	27 (4.2%)	7%
Other	15 (2.3%)	4%

A service in Leicester assessed referral rates of South Asian (n=2070) and White SUs (N=2070) over 15 years (Abbas et al., 2010). The study found that South Asian females were under-represented, constituting about a third of that expected given their population size in the local community (Abbas et al., 2010). Another 10-year study in Leicester suggested that the South Asian group were under-represented at the SEDS since they only made up one-quarter of referrals (Ratan et al., 1998). The authors proposed that members of this group may need to reach a higher clinical threshold to be considered appropriate for the service or may not want to receive a referral to a SEDS (Ratan et al., 1998). Nevertheless, a 34-year database (1960-1993) of SUs seen at a National Catchment Service in the UK found that the ethnic minority group (i.e. mixed, other, Black and Asian) and White SUs were similar in terms of clinical variables and referrals which suggested equal access. The study also found that the ethnic minority group was referred after a shorter duration of presenting with AN (Soomro et al., 1995).

In the ancillary literature, one US study of ethnic minorities showed that they were less likely (at trend level, not obtaining statistical significance) to seek treatment for their ED in 1.5 to 2 years following their participation National ED screening programme. Nevertheless, the study revealed that therapist bias in recognition of ED features was a more significant barrier to access treatment of EDs in ethnic minorities programme (Becker, Franko, Speck, & Herzog, 2003).

1.8.5 Assessment

The assessment of EDs involves factors including the how ethnic minority FDEDs communicate their distress, whether they view the service as designed for their needs, how the therapists interpret ethnic minority FDEDs and whether the assessment tools apply to this group. Supporting this, a cohort study of SUs in South London suggested that the under-representation of ethnic minorities may in part be due to therapists or referrers being influenced by the SWAG stereotype and therefore are less likely to ask ethnic minorities relevant questions about their ED features (Waller et al., 2009).

Within SEDs, therapist utilise diagnostic questionnaires and interviews to support their assessment of the ED. The tools to assess ED features have not been widely validated in ethnic minorities within the UK, and cultural constructions of some eating behaviours differ across ethnic groups. Ethnic minorities might be overlooked by assessment tools due to the subtle differences in presentation outlined in section 1.8.1. These include the suggestion that South Asian FDANs are less likely to report a preoccupation with weight and shape and more likely to report a loss of appetite. The authors proposed that this could explain why this group were significantly less likely to receive a diagnosis of AN at assessment (Tareen et al., 2005).

Mumford, Whitehouse, & Platts (1991) completed a factor analysis of EAT and BSQ scores by British South Asian and White FDEDS which supported cross-cultural equivalence of these measures (Cooper et al., 1987; Garner et al., 1982). However, the validity of applying these questionnaires to South Asian FDEDs may be questioned since they might place different constructions on the questionnaire items. For example, one of the questions in the EAT is 'I cut my food into small pieces' which refers to a behaviour often used by people experiencing AN (Garner et al., 1982). This question

may lack relevance to some South Asian food such as rice or chapati which may not require cutting or habitually involve the use of a knife and fork (Mumford et al., 1991). As such quantitative assessment tools might underestimate EDs in ethnic minorities and therefore should be used alongside clinical judgement. Therapists perspectives on using such tools for ethnic minority FDEDs has not been explored in research.

1.8.6 Treatment

In the UK, ethnic minority FDEDs are more likely to experience low treatment rates (Sinha & Warfa, 2013). For example, Abbas et al. (2010) examined referrals of South Asian and other ethnicities in Leicester. The analysis showed that South Asians were significantly less likely to be offered interpersonal psychotherapy than other ethnic groups (15.4% vs 42.3%, p=0.03). Moreover, South Asians were twice as likely to be offered guided self-help (i.e. a computerised self-help programme with input from a nurse or therapist), although this comparison did not reach significance so should be interpreted tentatively (23.1% vs 11.5%, p=0.27) (Abbas et al., 2010). However, a South London catchment study (n=648) found that types of treatment offered between ethnic minorities and White SUs did not differ substantially (Waller et al., 2009). These contrasting findings could be due to methodological differences or differences in the way in which SEDs are accessed and treatments delivered.

A focus group of ethnic minorities in Sheffield indicated help-seeking was hindered by slow recognition of EDs by SEDS and GPs (Chowbey et al., 2012). The authors reported that some services failed to consider religious practices, norms about food and body image or the impact of poor past experiences with services (Chowbey et al., 2012).

There have been no randomised controlled trials (RCT) of therapies that have looked at specific outcomes for ethnic minorities FDEDs in the UK. Lacey & Dolan (1988) presented five case studies of Black and Asians FDEDs in London, concluding that responses to treatment were inadequate. Their interpretation of poor outcomes may be, in part, due to selection bias whereby the study assessed only ethnic minority FDEDs who had experienced significant trauma due to family discord and separation

from their mothers. The outcome may also be due to the therapists interpretation of what is deemed to be 'recovered'.

1.8.7 Concluding Summary

In conclusion, Literature Review II found an additional 10 papers that had exclusively researched British ethnic minority FDEDs. The research indicated that ethnic minority FDEDs might be more likely to present with non-fat phobia AN or with overt BN symptoms (Tareen et al., 2005; Waller et al., 2009). Nevertheless, there was a suggestion that this might be due to a referral bias, whereby only those who are severe enough can obtain specialist help (Waller et al., 2009). Research also suggested that acculturation is a specific risk factor for ethnic minorities, although a systematic review came to the overall conclusion that both greater and lesser acculturation is a risk factor for EDs (Bryant-Waugh & Lask, 1991; Shekriladze & Tchanturia, 2016). Lack of attunement to culturally diverse features at assessment was thought to lead to reduced referral and treatment rates for ethnic minorities (Mumford et al., 1991). However, research suggested that reduced treatment rates might also be explained by familial shame or on the contrary greater support from the familial network (Chowbey et al., 2012; Wales et al., 2017). Lastly, there have been no research trials investigating clinical outcomes of therapy for ethnic minority FDEDs. However, there was some indication that services were more likely to offer ethnic minorities guided-self-help therapy and less likely to actively consider norms around food and religious practices (Abbas et al., 2010).

1.9 Current Research

1.9.1 Clinical Relevance

This research aims to identify areas that require attention to improve the identification and treatment of ethnic minority FDEDs in the UK. The present study explores therapists' experiences of working with ethnic minority FDEDs in SEDS. This perspective is relevant since therapists are part of the system that determines whether ethnic minority FDEDs receive treatment and the quality of care they receive. Firstly, the research aims to provide an insight into ethnic minority FDEDs, through the perspectives of the therapists who work with them and exploring what working with this group means to the therapists themselves. Secondly, this research aims to explore how therapists perceive and work with cultural concepts.

It is acknowledged that this is only one perspective, and inevitably there will be differences between what SUs and therapists view as relevant. Therapists might be able to offer the breadth of their experiences of working with ethnic minority FDEDs. They will be able to give insight in the context of the theoretical perspectives that they adopt when working with this group such as the recommended therapy models, the ICD-11 diagnostic criteria, NICE guidelines (2017) and their strata; psychological, economic, social and biological amongst others (Bhaskar, 1978). Their reports will elucidate what they struggle with, their assumptions, what they feel needs to change and what they report as their training needs.

A similar methodology was adopted in two recent UK studies and one US-based investigation which all concerned therapists' reports of working with ethnic minority FDEDs (Chowbey et al., 2012; Smart et al., 2011; Wales et al., 2017). These studies provided insightful findings however they have been said to suffer from methodological issues relating to, not focusing on the therapists' experience, integrating reports by therapists and SUs in the analysis (Chowbey et al., 2012; Wales et al., 2017) or being conducted outside of the UK (Smart et al., 2011).

1.9.2 Research Questions

- 1. What are therapists' perspectives on how ethnic minority females diagnosed with EDs access SEDS?
- 2. What are the therapists' experiences of working with ethnic minority females diagnosed with EDs in SEDS?

2 METHODOLOGY

2.1 Chapter Overview

This qualitative study explored therapists' experiences of working with ethnic minority FDEDs using a semi-structured interview. This chapter will begin by outlining the epistemological approach of the study. Critical ethical issues will be described, followed by a reflexive account to define the author's position concerning this research.

2.2 Design

2.2.1 Epistemology And Ontology

The epistemological approach of this research was critical realism (CR). Critical realism is associated with the works of Roy Bhaskar (Bhaskar, 1978, 2010, 2016). It is an approach that lies between the opposing views of positivism and relativism (Bergin et al., 2008; Danermark et al., 2019; Robson, 2002; Wainwright & Forbes, 2000). In the following, positivism and relativism are elucidated upon, including how these approaches contribute to and contrast with CR. After that, an explanation of how the CR approach adds to the present research will be provided.

Realism falls on a spectrum between naïve and critical. A naïve approach refers to the idea that knowledge about FDEDs equates to fact since it is value-free (Robson, 2002). Positivism proposes that this universal reality can be verified and tested through quantitative measures of psychological distress. However, in practice, this position is limited since it often confuses the causation and explanation of EDs with the prediction (Forbes & Wainwright, 2001; Frauley & Pearce, 2007).

In comparison to positivism, CR employs qualitative approaches to understand EDs. It investigates the causal mechanisms of EDs, in terms of how it exerts the effect if it was triggered and what circumstances gave way to the condition (Sayer, 1999). CR appreciates the stance of positivism to make attempts to investigate reality. However, in contrast, CR proposes that a cautious and critical approach should be taken (Bentall

& Pilgrim, 1999). A critical stance is required because the domain of the real is broader than what is experienced directly or indirectly (Collier, 1994).

Critical realism appreciates that social constructionism enables biased concepts to be replaced with concepts that are more useful clinically (Bentall & Pilgrim, 1999). However, it proposes that diseases are more than just a social construct since the reality of disease cannot be exhausted by paradoxical descriptions (Littlejohn, 2003). Critical realism proposes that what constitutes a mental health problem may exist beyond our discourse. Furthermore, CR proposes that it is not reality that is socially constructed. Instead, it is our theory of reality and the methods used to investigate this which are socially constructed (Bentall & Pilgrim, 1999). Theories include those of class, race, gender, linguistics and culture. Therefore CR proposes that there are different valid perspectives of reality, although CR rejects the social constructionist view that there are multiple realities that are socially constructed (Bentall & Pilgrim, 1999).

Critical realist ontology goes beyond a relativist and a positivist approach. Critical realist ontology begins with the theory of existence and identifying what 'is'. From the CR position, EDs and their meanings are real even if these entities are not directly observable. CR epistemology uses the theory of knowledge and understanding to query the creation and dissemination of knowledge about EDs in terms of how it relates to truth, beliefs and justification (Bhaskar, 1978). In CR, the reality is both differentiated and stratified to include multiple social and natural domains that include empirical, actual and real (Bhaskar & Danermark, 2006). Strata can consist of, psychological, social, economic, biological, and the physical, amongst others (Bhaskar, 1978). CR accepts there is an ontological gap between what happens; what we experience; and the mechanism which produces the events (Danermark et al., 2019). This reference to a reality that is independent of our perceptions and theories distinguishes CR from other ontologies which only account for empirical or actual strata (Sayer, 1999).

Furthermore, CR acknowledges epistemological constructivism which proposes that the viewpoint on psychological problems is inevitably socially constructed. Therefore, CR proposes that no perspective of reality is correct or independent (Putnam, 1999).

Therefore both the perspectives of SUs and therapists should be equally explored and weighted.

The perspectives of SUs and therapists may differ since the social setting in which ED diagnoses are discussed by professionals differs from the setting in which the psychological distress was generated. As such, we cannot assume that the vocabulary for emotions has a consistent meaning within a culture or between therapists and SUs (Bentall & Pilgrim, 1999). While SUs may oppose or critique the views of professionals, they also in part, internalise therapists discourses around EDs (Bentall & Pilgrim, 1999; De Swaan, 1990). What is defined as an ED by therapists, influences the SUs understanding and the interventions that the therapists provide (Payne, 2006). This position highlights the importance of gaining perspectives not just from SUs, but also the professionals involved in their care.

2.2.2 Rationale For The Qualitative Approach

The vast majority of studies in the field of EDs have favoured the quantitative paradigm, which creates the impression of objectivity and scientific results (Breuer, Mruck, & Roth, 2002). In comparison to quantitative methodology, which assumes a universal reality, qualitative methodology assumes a dynamic and negotiated reality and the possibility of existence beyond what is quantifiably measurable. Quantitative methodology often confuses the causation and explanation of experiences working with FDEDs, with prediction (Forbes & Wainwright, 2001; Frauley & Pearce, 2007). In comparison, qualitative methodology allows for the nuances in the reality of clinical work to be accounted for in a manner that might be overlooked by a quantitative approach (Whitney, Currin, Murray, & Treasure, 2012).

2.2.3 Rationale For Thematic Analysis

Thematic analysis (TA) was used to analyse the interview data. TA is particularly useful in exploring how therapists as a group conceptualise the specific phenomena of working with FDEDs (Joffe, 2012). TA allows the researcher to identify patterns across the entire dataset, as opposed to Interpretive Phenomenological Analysis, which focuses on the unique experience and characteristics of each participant. Furthermore, the TA approach lends itself to slightly larger sample sizes.

Thematic analysis aims to look beyond what therapists report and consider what conditions led to their experience with FDEDs and how this experience was triggered (Sayer, 2000). TA aims to capture the complexity of therapists experience while allowing for patterns of meaning to be found (Braun & Clarke, 2013).

Thematic analysis aims to understand the approach to therapeutic work with FDED from the therapists perspective, their subjective worlds and meanings (Yardley, 2000). As such, this approach favours the importance of reflexivity and contextualisation. Therefore this paradigm incorporates the influence of personal, social and local factors, in which the experience of the therapist working with FDED was generated (Breuer et al., 2002).

2.2.4 <u>Developing The Interview Schedule</u>

Individual interviews were chosen over focus groups since this method allowed for ease in discussing the sensitive topics around race and therapeutic work with ethnic minorities (Willig, 2013). The dyadic interaction in interviews allowed for more disclosure and rich details. In comparison, focus groups encourage group dynamics which may produce less detail and a high group consensus.

Semi-structured interviews were chosen since it allows for the same conceptual points to be covered across respondents. Furthermore, this type of interview allows for open responses, flexible wording of the questions, interaction and clarification of responses. In comparison, structured interviews encourage limited responses, and unstructured interviews have no set questions or order (Berg, 2007).

The interview schedule (Appendix 7) was designed considering the research aims and mapping the range of topics to be covered (Spradley, 2016; Willig, 2013). Appropriate questions were developed for each topic. Open-ended questions were used with a list of prompts and probes, ensuring that the interview was not too directive. Secondly, the sequencing of questions was considered. The interview schedule started with an ice breaker, descriptive questioning of the therapists' role and previous work with FDEDs. Structural questions explored how therapists think about the frameworks they use to understand FDEDs, such as the NICE-recommended treatments. Evaluative

questions were used to explore how therapists feel about taking culture into account (Spradley, 2016; Willig, 2013).

The interview schedule and demographic questionnaire were reviewed by Dr Lucy Serpell, who is an expert in the field of EDs and contributor to the recent NICE guidelines for EDs (2017). Amendments were made following suggestions. Finally, the interview schedule was piloted with a therapist who had previously worked within SEDS. The feedback was used to amend the interview schedule and consider opening and closing questions, the sequencing of questions, the wording and probes to ensure in-depth answers.

2.3 Participants

2.3.1 Sample Size

The study recruited 12 therapists who had previously worked with ethnic minority FDEDs in a SEDS. The sample size required for a thematic analysis is an area of debate (Fusch & Ness, 2015). It has been proposed that a sample size should be chosen, which gives the best opportunity to reach data saturation (Fusch & Ness, 2015). Nevertheless, the exact number is not pre-determined and might be based on opportunity (Bernard, 2012).

Data saturation is obtained when there is no new data that can be obtained, further coding is not feasible, and therefore the study can be replicated (Guest, Bunce, & Johnson, 2006). At the stage of saturation, the data obtained should be rich in terms of quality and thick in terms of quantity (Dibley, 2011). It is noted that the researcher cannot separate their perspective from the cultural world of their participant (Jackson, 1990). As such, their lens, including biases, values, and ideologies, can influence when they deem data-saturation to be reached (Bernard, 2012).

2.3.2 Ethnicity

The sample was mixed in terms of ethnicity. There is no published data of the ethnicity of therapists working in SEDS in London. However it was hoped that the participants would reflect the therapists that SUs encounter in London SEDS. Ethnicity is a complex and nuanced construct that has a different meaning to every individual

(Duncan & Trejo, 2017). Ethnicity has different levels according to acculturation and can range from the first, second and third-generation. It was hoped that this nuance would give rise to rich data.

2.3.3 Inclusion Criteria

The following inclusion criteria were applied:

- Therapists worked in a therapeutic role including clinical/counselling psychologist or family/systemic therapist
- Therapists had at least one year's experience working in a SEDs
- Therapists had provided NICE (2017) guidance recommended treatments (i.e.
 CBT or FBT) to at least two ethnic minority female service users aged 12 to 65
- Therapists were any age, ethnicity, and gender
- Communicated fluently in English

2.4 Procedure

2.4.1 Recruitment

Participants were recruited using snowballing and convenience sampling to obtain a representative sample of therapists in London. Participants were recruited using the study flier (Appendix 2) through the researcher's professional network via word of mouth, online social networks, Linkedin or directly approached. Participants were offered £35 for their time from the researcher's funds, such amount not being to secure their participation but in recognition of the fact, therapists needed to travel in their own time to a neutral non-NHS site (i.e. UEL or local library) and are typically educated to doctoral level and paid accordingly. Also, therapists typically work long hours (37.5 hours a week or more) and have very high caseloads, which include emotional distress. Therefore, this sum for participation took into account that therapists needed to give up 2 hours of their spare time outside of work for the study. By agreeing to pay their expenses, this helped to ensure that scheduled meetings were not cancelled or postponed and research timelines were met. All participants were informed that this research could contribute to the broader evidence base that may lead to more effective strategies in the provision of services and treatment of ethnic minority FDEDs.

2.4.2 Initial Contact

Interested participants were emailed or posted the Consent Form (Appendix 4) and Participant Information Sheet (PIS) (Appendix 3) depending on their preference. Time was given to allow for consideration and an opportunity to answer questions about participation. If willing, the interview was arranged at a convenient date, time and location which included via skype or telephone or a local library room.

2.4.3 Collection Of Demographic Information

Participants were asked to complete a short demographic questionnaire before coming to the interview. This questionnaire covered age, gender, ethnicity, occupation, years of experience working in SEDS and training needs (Appendix 6).

2.4.4 Semi-Structured Interview

The interview was conducted using a semi-structured interview schedule (Appendix 7) as described in section 2.2.4. Before starting the interview, the participant was allowed to ask questions and consent to take part and audio record the interview was revisited. The semi-structured interviews with the participants lasted between 45 minutes and 75 minutes. At the end of the interview, participants were debriefed and consent to use the anonymised data was checked.

2.5 Ethical Considerations

2.5.1 Ethical Approval

The study was registered with, and ethical approval was obtained from UEL (Appendix 8). The design of the study was informed and complied with the British Psychological Society's, Code of Human Research Ethics (British Psychological Society, 2014).

2.5.2 Informed Consent

Participants were provided with the PIS (Appendix 3) outlining the study details and given a minimum of a week to decide whether they wished to take part in the study. This time for reflection was intended to reduce any feelings of coercion to take part in the study. Participants were allowed to ask the researcher questions before opting into the study and signing the consent form (Appendix 4). Efforts were made to ensure that consent was an ongoing process throughout participation (British Psychological

Society, 2014). Participants were unaware of the exact interview questions and, as such, they might have wished to withdraw their consent during the study. This present research enquired about sensitive topics addressing how therapeutic work is impacted by race. Therefore, consent was verbally obtained at the start and revisited at the end of the interview audio recording. The participants were made aware that they could withdraw consent to participate or remove their data within a three-week window from the time that they participated in the study.

2.5.3 Confidentiality

All participant information was treated confidentially and in accordance with the Data Protection Act 2018. Consent forms were scanned and held as electronic data on a password-protected computer that was separate from the interview data. Hard copy versions of consent forms were shredded once scanned. Audio-recorded interviews and transcribed material were anonymised and immediately transferred to a password-protected computer file on a UEL secure network. All personal information and contact details were deleted after data collection. Scanned consent forms and audio recordings were deleted once the study had ended.

Anonymised audio recordings and transcribed interviews will be stored for three years after which point they will be destroyed. Given the relatively limited number of therapists working in EDs in London, enhanced anonymity was applied during transcription (Thompson & Chambers, 2011). Each participant was given a pseudonym, and any identifying details such as names of people or places mentioned were anonymised. Age and job titles were referred to as a range or broad category. Interview quotes used in this thesis were carefully selected and kept brief to ensure anonymity.

2.5.4 Possible Distress

The interview was not designed to cause discomfort and care was taken to conduct it sensitively. The study required reflection on clinical work which is considered a standard practice for therapists. Nevertheless, the topics discussed in the interview may have triggered a sense of race-based stress and discomfort (DiAngelo, 2011). Given my position as an ethnic minority who has previously worked in SEDS, therapists may have felt they were being tested on the quality of work they have

provided. However, it is hoped that the participant information sheet and debrief (section 2.5.5) at the end of the study clarified the position of the study, which is to elucidate information in order to improve care for ethnic minority FDEDs. Furthermore, the position of the study was reiterated during the interview to ensure that participants were kept at ease. The aim was to create an open and non-judgemental space during the interview.

Participants have the right to expect that the information they provide will not be identifiable and be treated as confidential. This required special consideration since some of the participants were recruited from the researchers own professional network. Given the interview questions surrounding the participants' opinions of their service management at their ED service, there may have been considerable awareness about making sure their responses were confidential, resulting in social desirability bias. Therefore efforts were made throughout the research process and interview to assure them of confidentiality and enhanced anonymity.

2.5.5 Debrief

In line with ethical guidelines (BPS, 2014), each participant was debriefed at the end of their interview using a debrief sheet (Appendix 5). The debrief was an opportunity to revisit the content, reflect and raise concerns with the researcher. The debrief sheet also provided the researcher's and supervisors contact details to communicate their concerns and gain support if they needed. Participants were also be reminded that they have the opportunity to withdraw their data.

2.6 Analytic Approach

2.6.1 Analytic And Interpretive Process

Inductive TA was used to generate an analysis from the bottom up (Braun & Clarke, 2013). Therefore the themes were derived from the data as opposed to existing theories. The aim was to develop a theory, as opposed to test an existing theory since there is limited data in the area. Hence, specific observations were interpreted to induce broad generalisations (Braun & Clarke, 2013). The data was coded for semantic and latent codes. The semantic codes were data derived and a succinct summary of the explicit content. The latent codes were implicit interpretations of the

data. Given therapists' position of power and 'expert status' in comparison to SUs, a suspicious interpretation was applied, and the possibility of latent meanings was held in mind (Willig, 2014). Attention was also paid to descriptions that were contradictory and suggestive of possible internal conflict. A curious and an empathic stance was applied to consider subjective meanings behind responses. Given the critical realist position, the data were interpreted considering the psychological, social and economic strata in which the experience was generated (Bhaskar, 1978). Inevitably the researcher's standpoint, disciplinary knowledge and epistemology also shapes the analysis and this is explored further in Section 2.7.

2.6.2 Transcription Method

Familiarisation with the data took place during transcription. The audio material was transcribed using the system of transcription conventions by Banister and colleagues (2011). This method advocates a simple word for word transcription. Names were replaced by pseudonyms and details that identify people or places were replaced with words within (). When the information was ambiguous, contextual information was provided in ['inaudible']. Words spoken with emphasis are <u>underlined</u>. For readability, the transcript was punctuated. It is the view that in TA, the pauses are of limited analytical value and therefore not recorded. Other interruptions and overlapping talk are marked with /. Laughter during the interview is coded in brackets []. The final transcript incorporated line numbers to allow for convenient referencing in the analysis, and results write up (Banister et al., 2011). While listening to each interview audio recording, ideas and notes were recorded in a reflective journal (Appendix 13) and used in the analysis and interpretation.

The TA followed six phases, not necessarily in consecutive order (Braun & Clarke, 2006):

2.6.2.1 Data immersion

The researcher conducted the interviews and transcribed them. These activities represented the start of data immersion. Following this, each interview transcript was actively read several times over to search for patterns. Double consciousness was applied, which refers to the ability to listen and hear what has been said while

simultaneously remaining critical (Braun & Clarke, 2013). During this, notes were written to record reflections before the formal coding began.

2.6.2.2 Generating initial codes

Patterns of semantic content were identified, organised and coded to the research question (Braun & Clarke, 2006). The complete coding approach was used to identify anything of interest to the research question within the entire dataset.

2.6.2.3 Searching for themes

A theme captured something important concerning the research questions and represented a patterned response or meaning. Reflective notes were used to consider how codes could form overarching themes. Braun and Clarke (2013) propose that the researcher should actively develop themes from the coded data and create potential patterns. Following this, the codes were sorted into possible themes and produced an initial working thematic map (Appendix 11) of candidate themes and sub-themes.

2.6.2.4 Reviewing themes

Themes were reviewed and refined according to the thematic map (Appendix 12). The themes and sub-themes were also reviewed. Further coding and re-reading was done by reviewing for coherence and distinctiveness.

2.6.2.5 Defining themes

A detailed analysis of each theme was written. An iterative process was applied to form themes into a hierarchy that fit into a story within a broader story. Each overarching theme had sub-themes that represent meaning within the data.

2.6.2.6 Producing the report

A report was written that illustrated the story and provided an analytic narrative that makes an argument concerning the research questions. Each theme was supported by vivid examples to capture the themes and their sub-themes.

2.7 Reflexivity Statement

The research process and outcome is inevitably mediated by the author's identity and role as a researcher. This process is referred to as the reflexive process (Russell & Kelly, 2002). This subjectivity replaces the idea of the value-free objective researcher, and the inter-subjectivity between participants and researchers is argued to enhance the research process (Wheatley, 1992). Instead, research outcomes are considered to be due to co-authorship and active participation (Russell & Kelly, 2002).

The role of reflexivity refers to critical reflection on the role of oneself on the research process. It is proposed that researchers have both insider and outsider roles in this process. The insider position refers to the identities that we share with our participants, and outsider refers to the identities that we do not share. A person may have multiple identities that are shared or not shared. This makes the researcher intertwined and inseparable from the interpretations made. Attention is paid to ensure that the author differentiates their own experiences from the experiences of the participants.

The author's identity and role as the researcher has inevitably influenced how the data was analysed and the interviews conducted. During the research process, the author added to a reflective journal as a way of creating a reflective space and awareness. The following is a summary of the author's identities and experiences that are relevant to this research.

- During my training, I have learnt that I have been a 'Good Ethnic Mainstream Minority' (GEMM) therapist (Hardy, 2008). GEMM therapists are trained not to mention race at work, accept colour blindness and work harder than other colleagues to be successful (Hardy, 2008). I was aware of how the questioning about topics of race in this research may have caused me to diverge from this GEMM role. This discomfort may have led me to probe less around questions concerning this or pay less attention in the interpretation phase.
- I am a British Indian who was born in the UK in the home counties and considered myself to have left-centrist socio-political views. These identities led me to feel the same, but different from the ethnic minority FDEDs the therapists refer to, and as such, I am aware of feeling protective over this group.

- I have previously worked in NHS SEDS in London and have provided psychological interventions to ethnic minority FDEDs and worked alongside therapists providing similar interventions. This role allows me to identify with the position and role of my participants. Given the closeness of this position, it meant that I could probe and ask relevant questions, but also may have led to me over-empathising without critiquing and the participants providing socially desirable answers as opposed to their true feelings.
- I have worked in academic settings and produced a PhD using quantitative research methods to investigate the neuropsychological and biological causes of EDs. I was aware of how this identity influenced, my assumptions, the results write-up and terminology used during the interviews.
- As a trainee clinical psychologist, I have been trained in social-constructionist conceptualisations of psychological distress. Given the critical realist position of the research, I recognised that the experience of therapists could not be exhausted by the descriptions they provided. As such, I paid attention to hidden meanings beyond the descriptions of their experience.
- As the principal researcher in this study, I was aware of power the dynamics that manifest within the researcher-participant relationship (Råheim et al., 2016).

3 RESULTS

3.1 Overview

This chapter contains information about the interviewed participants followed by a thematic map of the themes derived from the analysis. Subsequently the analysis of the interviews is presented, supported by examples from the data.

Twelve participants were interviewed. A summary of their demographic information can be seen in Table 2. Pseudonyms were used to maintain anonymity. SEDS is a narrow speciality, therefore, to ensure anonymity each participant's ethnicity and age have been presented using broad categories.

Two-thirds of the participants were either White British or White other (n=8, 67%); the rest were from ethnic minorities. The majority were female (n=11, 92%) and most reported their occupation as a clinical or counselling psychologist (n=11, 92%). Age ranged from 28 to 55 years old (median=36).

Table 2: Participant Demographics

Name	Age	Ethnicity	Years	Occupation
			working in	
			SEDS	
Rua	40-44	Ethnic	2.5	Clinical/
		minority		Counselling psychologist
Katherine	40-44	White British	3.0	Clinical/
				Counselling psychologist
Mary	25-29	White British	3.0	Family
				therapist
Cyra	30-34	Ethnic minority	3.5	Clinical/ Counselling
		illinority		psychologist
Sachi	35-39	Ethnic	4.5	Clinical/
		minority		Counselling psychologist
Beth	30-34	White British	6.0	Clinical/
				Counselling psychologist
Saskia	25-29	White other	6.0	Clinical/ Counselling
				psychologist
Dominic	55-59	White other	10.0	Clinical/ Counselling
				psychologist
Amaya	40-44	Ethnic minority	11.5	Clinical/ Counselling
		illinority		psychologist
Jessica	50-54	White British	15.0	Clinical/ Counselling
				psychologist
Katrina	30-34	White other	15.0	Clinical/
				Counselling psychologist
Avery	35-39	White British	16.0	Clinical/ Counselling
				psychologist

3.2 Questionnaire Data

The following information was gathered from the self-report questionnaires to gain more information about the sample characteristics before approaching the analysis of the interviews. Self-reported confidence (score out of 10) for working with ethnic minority FDEDS ranged from 5 to 8 (median: 8). The number of years working with FDEDS ranged from 2.5 to 16 years (median: 6). As can be seen in Figure 2, the number of years working with FDEDS has little association with self-reported confidence in working with ethnic minority FDEDS.

Participants reported working with the following ethnic minority types by the number of times: South Asian types were reported 28 times, Black ethnic types reported 17 times, Arabic reported six times and East Asian types reported five times. Six participants (50%) reported that clients from an ethnic minority background were proportionally represented on their caseload in relation to the demographics of the area, five explained that representation was lower, while one participant was unsure.

Participants reported that the most common training on culture offered was the training that they received during their clinical/counselling doctorate or systemic therapy training (n=6, 50%). The second most common training identified was the mandatory NHS employment equality and diversity training (n=4, 33%). In response to the question about what their further training needs were, six participants either left the section blank or said they were unsure. The remaining participants (n=6, 50%) explained that their training needs could be achieved through training in ED therapeutic models, FBT, motivational interviewing, CBT for EDs and through continuing professional development.

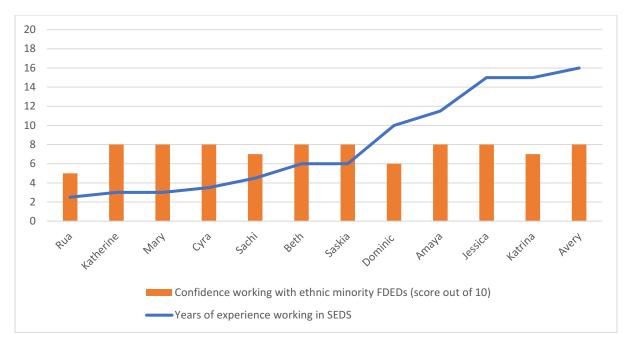


Figure 2: Years of experience working in SEDS versus confidence in working with ethnic minority FDEDs.

3.3 Thematic Map

The final thematic map can be seen in Figure 3, which depicts the three overarching themes and subthemes. Before creating this, two working thematic maps were developed to look for potential patterns in potential themes (see Appendix 11 and Appendix 12). These patterns were drawn from intermediate (Appendix 10) and initial codes. Furthermore an example of a coded interview transcript is provided in Appendix 9 and the reflective journal kept throughout the research and analysis appears in Appendix 13.

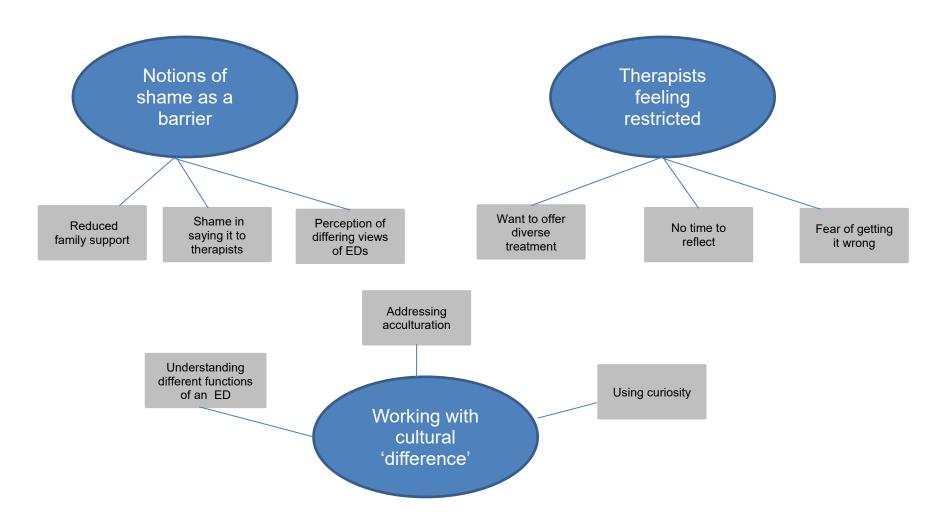


Figure 3: Map of overarching themes and subthemes

3.4 Analysis

The interviews aimed to hear therapists' perspectives on how they think ethnic minority FDEDs accessed care from SEDS. This involved exploring whether participants felt ethnic minority SUs were proportionally represented at SEDs, whether they felt that there were any barriers to accessing help and treatment, and if so, why they think that might be the case.

The second aim was to hear therapists' perspectives on their work with ethnic minority FDEDs in terms of what it means to the therapists themselves, their experience and their meaning-making. Participants were encouraged to think about whether they had provided any adaptations relevant to cultural differences and, if so, whether they felt comfortable doing so. On a broader systemic level, participants were asked how cultural adaptations fit within their service and, in a practical sense, whether these adaptations were possible.

3.4.1 Theme 1: Notions Of Shame As A Barrier

The words 'stigma' and 'shame' were used to refer to something that participants believed ethnic minority FDEDs and their families experienced concerning the ED diagnosis and as a barrier to receiving help. *Shame* was referred to as a nebulous concept as opposed to fixed. Participants had different ideas about shame and how it works in other cultures, and this appeared to influence their therapeutic work. This included not challenging shame or assuming EDs in certain cultures are taboo and linking this to a negative interpretation of parents. The sub-themes are described in the following sections.

3.4.1.1 Subtheme 1: Reduced family support

Participants reported the belief that FDEDs' shame around their ED meant that they excluded their family from therapy sessions. For example, Katrina explained:

"Thinking about a young person who didn't want to come with their parents because they felt that there was, it was kind of secretive and shameful to have an eating disorder, and they didn't want their parents involved. So, for example, we didn't involve parents at all." (Katrina, Line 454-458)

Here Katrina is telling us that she perceived that the ED felt secretive and shameful for this SU. In this case, she felt that shame acted to reduce family support. Katrina has a clear and empathic perception of how her SU sees her ED, in her use of words 'secretive and shameful'. She then suggests working with her SU as a team, implied by using the word 'we', to see that her needs were met by not including the parents. The suggestion that parents were not involved at all is perhaps not sustainable in the long-term, given the nature of work with young people and children. Given the difficulties associated with shame described by Katrina, it is possible that by taking these steps, she was in one sense colluding with it.

In the following extract, Beth explains how she thinks that stigma surrounding mental health can make it difficult for ethnic minority families to discuss and seek help for their child:

"...because for whatever reason, it hasn't been picked up at home, maybe because of a stigma thing or within their culture it is kind of taboo to talk about and then it actually took the teacher to notice." (Beth, Line 55-58)

Beth does not imply she knows the cause of this situation since she says 'for whatever reason'. However, she presents the possibility of culture being a factor and then explains how she understands this to work. It is noted that Beth was asked 'what factors influence how ethnic minorities are referred to SEDs' and this line of questioning might encourage her answer to focus on culture. Nevertheless, Beth suggests that 'it has not been picked up at home' and implies this is due to their culture. This may be seen to cast blame on the parents and implies they have been neglectful (i.e. rather than not wanting to contact services because they believe they can help their child best, for example). This assumption could be viewed as pejorative. Furthermore, Beth positions the parents negatively as not noticing, and compares them to the teachers who it took to notice and are therefore viewed positively. By

focusing on ethnicity, it restricts a wider observation that topics around the body are potentially a source of shame and reticence, not solely for ethnic minorities.

In the following quote, Amaya implies that she is not sure why ethnic minorities have delayed access to SEDs, although she speculates the reason is shame. She explains the SUs have not directly stated that shame is the reason for not asking for help from family. This also suggests that the reasons may not have been explored in therapy:

"So they've kind of gone a bit longer and not asked for help as much. Not as early, I think. And I don't know why that is. I can speculate that it's shame." (Amaya, Line 281-283)

"...I was thinking of and then a Black Caribbean, or Black African, I'm trying to think. But both of them specifically said that their families were not aware of their difficulties and what was going on, whereas that wasn't quite what was experienced by the White students, their families were aware." (Amaya, Line 288-292)

Amaya says her clients told her their families were not aware, so to her, it is not merely a perception or idea; she is saying they directly communicated this. Amaya does not reveal whether she thinks it is better or preferred for families to be aware. She then makes sense of this by assuming it is because of race, even though one is Black African and one is Black Caribbean which means there could be differences or other things, asides from the race, that these two SUs have in common which drives the connection. The implication of Amaya discussing shame and then families not being aware suggests that she links a lack of disclosure to shame. As such therapists' ideas can themselves become barriers or prohibitive.

3.4.1.2 Subtheme 2: Shame in saying it to therapists

Participants perceived shame to impact how ethnic minority FDEDs communicated their needs to therapists and SEDS. Specifically, there was a perception that distress was not communicated or that there was an avoidance of talking about mental health, instead favouring the physical health perspective.

Here Katrina explains that features of the ED are not disclosed or perhaps avoided by FDEDS:

"Treatment when people entered into treatment, the body image concerns where people seemed less and less able to talk. And I wondered if there was more shame attached to that." (Katrina, line 179-181)

"And, and so it was easier for them to describe things in terms of struggling to eat for physical reasons or not feeling hungry." (Katrina, line 183-184)

Katrina's quote might be seen as somewhat ambiguous. She appears to suggest that when ethnic minorities first enter treatment, their body image concerns are not revealed, they are ashamed and less likely to talk, and she wonders whether this might be due to shame and culture. Katrina goes onto explain that physical aspects or explanations of the ED are spoken about with more comfort by the SU. Indeed, in society, the physical health model may have fewer connotations of shame in comparison to mental health problems. As such, it is implied that SUs seek help by adopting the physical health perspective.

Participants explained that FDEDs communicated they were unable to eat due to problems with their stomach or gastrointestinal issues. Here Avery describes how the SU she worked with described not eating due to physical stomach problems:

"But the reasons why they were malnourished, were all about like something being wrong with the stomach which I haven't really heard from White British women so much." (Avery, Line 456-458)

"But there was something almost like spiritual maybe about the stomach as like an organic, that it's like gone wrong." (Avery, Line 460-462)

Avery's use of the word 'organic', suggests she perceives SUs to assign the blame to a physical cause that the individual has little or no control over. The reference to something 'gone wrong' also implies a type of malfunction. Furthermore, Avery's reference to the 'stomach' as a cause for not being able to eat, implies a recognition of a reduced distinction between the mind and the body. Here Avery has cautiously put forward that these reasons for not eating are not typical of what she would encounter with White SUs.

Saskia appears more ambivalent about whether ethnic minorities communicate differently, with only one that comes to mind, that is minimising the psychological distress associated with EDs:

"... it's very easy for them to kind of say 'oh no, I do that, but that's not a big deal'. Or to kind of make it out like it's not really an eating disorder, it might just be you know, 'this is okay that I weigh my food" (Saskia, Line 163-165)

"...think as I said before about minimising and that's the only one that really comes to mind." (Saskia, Line 189-190)

'Minimising' implies making smaller and perhaps hiding the ED. In the previous quote, Saskia explains how she feels SUs attempt to normalise ED behaviours. She describes this as being seen by SUs as the 'easier' option, which is perhaps a questionable notion. Although she may be implying it is easier since it avoids having to confront the difficulties. This is similar to Katrina's perspective that avoidance of talking about the ED is perhaps easier since it also avoids the associated shame. She perceives this as a significant difference and more unique to ethnic minority FDEDs.

3.4.1.3 Subtheme 3: Perception of differing views of eating disorders
Participants perceived that ethnic minorities have differing views of EDs or understand
them differently. This was thought to be due to ethnic minorities knowledge or lack of
experience with the difficulties:

- "...parents from some ethnic minority groups may not have any experience of psychotherapy." (Dominic, Line 184-185).
- "...just mental health as a concept and that can be quite scary because people may think that it's going to be, this is something permanent that their children are going to be kind of marked for life if anybody hears about one of their children being, having a mental health illness may impact everybody else's chances in life." (Dominic, Line 186-190).

Dominic explained how the ED label, which is a mental health diagnosis, was perceived to have a cultural narrative synonymous with exclusion from society, blame and permanent scars. He interprets this observation as impacting not just the individual's health, but also their future and wider family. In this extract, Dominic appears to empathise and understand their position that mental health problems can be 'quite scary'.

Sachi understood this stigma, to be rooted in the way in which EDs were conceptualised from a different cultural viewpoint:

"I think there's different conceptualisation. So I've worked with one African girl and their family where they saw it as being like, possessed by like a gin and how for that, you wouldn't necessarily go to a doctor you, you would go to sort of more, turn to religion" (Sachi, Line 284-286)

Sachi's comments here suggest that the ED has been understood in a way that does not fit with Western views of mental health. She notices a different conceptualisation and seems to understand the family's actions given their interpretation of the ED as a possession. Nevertheless, there is a noticing of this perception being different and explaining delayed help-seeking.

Participants perceived ethnic minorities to have a different understanding of the ED, and this could be the reason for delayed presentation to SEDs. In the following quote, Mary directly compares White people with ethnic minorities. In the quote, it appears that she is guessing about this comparison as opposed to using evidence or data.

This comparison reveals an attitude that implies the reason for not accessing care is due to ethnic minorities not knowing about EDs:

"...if they really don't know much about eating disorders, they might not act early before they see any kind of physical deterioration, like when there are just changes in behaviour, whereas potentially people with the White ethnic background who perhaps had education in the UK that might know a bit more about these things?" (Mary, Line 138-142)

The quote focuses on seeking help only when there is physical risk and suggests that this is due to education. However, it does not explore other reasons why people might seek help later, such as family wanting to try help first. Mary refers to education as a factor that could influence understanding. It is suggested that, in implying that families do not have an understanding of mental health problems, Mary has taken a dismissive approach toward their perspective. Indeed, education in the UK may enforce a Western view of EDs that perhaps aligns with the ED models in which participants have been trained. Therefore, it is not just the level of education but also the application of different ways of thinking that impact how EDs are perceived and how help is sought.

3.4.2 Theme 2: Working With 'Cultural Difference.'

Dominic acknowledged his previous understanding that EDs are more likely to be associated with White or Western females. Some participants admitted to previously upholding this belief before their work in London SEDS. Dominic referred to the 'evidence' which suggests that he is comparing the SUs that he has worked with the research evidence of EDs, which is primarily based on Western populations. There appears a discord between therapists' practice-based evidence and what is learnt from the research and literature:

"I wouldn't have expected it because of the kind of, the myth about eating disorders very much a kind of White European or North American illness, but then there is lots of evidence that it's not the case, just they present in slightly different ways." (Dominic, Line 99-102)

3.4.2.1 Subtheme 1: Understanding different functions of an eating disorder The following section provides quotes which all explore the different ways participants interpreted the factors fuelling the disordered eating and psychological distress. One thing all these quotes have in common is how the perceived causes focus on areas outside of the topic of weight and shape concern.

Sachi felt that within some ethnic minority cultures, there were specific family scripts around interaction fuelling the ED, such as not defying your elders:

"And there was a narrative about you don't sort of challenge your elders, you don't speak back. You don't really have a voice you just go with. And I think she felt very oppressed. I think for her, there was defiance in not eating." (Sachi, Line 752-754)

There was the assumption that these interpersonal difficulties were more likely to be fuelling the ED. Sachi paints a picture of a challenging situation for the SU, who is left feeling oppressed and without a voice. She describes the SU as 'not eating' as a form of communication, allowing her voice to be heard and to challenge her elders. Furthermore, in using the words 'you do not really' Sachi, is perhaps stepping into the mind of her SU and immersing herself in their perspective.

Cyra thought that EDs have a different function for some ethnic minorities, outside of weight and shape concerns:

"But it's a control of emotions, for example, with ethnic groups, like, for example, starving themselves, you're controlling something, but it's not really weight and shape, doesn't come out as much. So, I have had this battle with certain clients where I'm for example using the CBT model." (Cyra, Line 514-518)

"...I might face some resistance because the person doesn't really identify with that." (Cyra, Line 519-520)

Cyra described a 'battle' when trying to work with ethnic minority FDEDs. She related feeling there was a mismatch between the evidence-based CBT model that guides her work and what the SU presents within therapy. She experienced feelings of resistance which she places externally because the SU does not fit or identify with the therapy model. Although she does not explain how this impacted the SUs care, it is noted that the use of words such as 'battle' and 'person does not really identify' has negative connotations and primarily focuses on the SU, as opposed to the CBT model.

Avery explains that she has observed how some ethnic minorities she has worked with have had histories of poverty, food scarcity or fleeing from war. She goes onto explain how she interpreted these factors may have made them vulnerable to the ED:

"Then also, some of the families I've worked with, they've really experienced a lot of food scarcity and they have had times when, you know, they lived in poverty and they haven't been able to eat well, and they've spoken about that. Or if they have had to flee countries, you know, where there's war, you know, that affected their eating." (Avery, Line 483 -486)

Avery's reference to these traumatic experiences might support the notion of interpersonal and emotional factors driving the ED, as Cyra and Sachi suggested. In this quote, Avery refers to a few factors; firstly, there is the idea she understands how food scarcity due to poverty might have influenced the meaning around food in the context of ED's. Secondly, there is the understanding that traumatic experiences such as fleeing war could affect the ability to eat.

3.4.2.2 Subtheme 2: Addressing acculturation

Participants observed that within ethnic groups, there were different levels of acculturation to Western norms:

"And this one girl, she was 15. She was quite heavily influenced by media. But she was born in this country. So, her ideas around beauty and thinness, which was constantly on Instagram. She was very influenced by Western ideas. The other people I've worked with were all a lot older. And I think they were all people that had immigrated here. So, I don't think they have the same kind of Western ideas around beauty." (Sachi, Line 721-725)

Sachi's quote, she notices differences in Western influence between first and second-generation ethnic minorities. Sachi has linked increased exposure to Western social media to being influenced by Western beauty norms and therefore increased risk of ED. She implies this is something that has a more significant impact on younger SUs. Sachi refers to 'Western ideas around beauty' and 'media' which goes on the assumptions that these have a common and understood meaning. This might reveal Sachi's presuppositions, and insight into how she understands this and therefore, how she makes sense of the SUs she works with. Sachi links the risk of Western influence to have a more significant impact on younger SUs and increased risk of ED.

Avery observes a somewhat more nuanced impact of acculturation in comparison to Sachi's more well-known ideas:

- "... I know the Afro Caribbean cultures, it's very revered to be larger and to have a different body shape to what traditionally we in White British culture or American culture has kind of said is the ideal but they might, that might be more protective..." (Avery, Line 516-519)
- "... I think also ethnic minorities groups experience more victimisation, more hostility, racism. Those negative life events could be important vulnerability factors." (Avery, Line 520-522)

Avery compares what she knows about the difference in body shape ideals in African Caribbean in comparison to White British. Throughout the passage, Avery switches between interpreting her own experience and that of ethnic minorities. When referring to White British culture, she refers to her in-group identity by referring to this as 'we' suggesting her ownership with this view. Nevertheless, she also postulates the risk of racism and hostility and her reference to it being ethnic minorities experience, switches to make it distinct from her own. It may be suggested that the scientific language used, such as 'life events' and 'vulnerability factors' suggests a detached or theoretical position about these ideas.

Rua goes on to explain how she feels there are challenges of 'living between' cultures:

"...living between two cultures which have quite conflicting standpoints. So I guess, I guess for some young people, they're at home with their very collectivist ideas at home and traditional, and then they're going into school, and it's kind of very individualistic exposed to two sets of ideas which can, I can imagine, know can be guite, guite difficult to manage." (Rua, Line 581-586)

She describes this as a balance to be maintained between the demands of both collectivist and individualist cultures. She is seemingly referring to living between the culture at home and the culture of society outside. This positions them as separate entities. She appears empathetic or understanding but perhaps over relies on her notions of culture and difference. She seems keen to try and understand on the one hand but also at not at ease with her questioning using the word 'I guess'. Rua treats her understanding as both true and speculation by using the phrase 'I can imagine'.

3.4.2.3 Subtheme 3: Using curiosity

Most participants reported using curiosity to attend to cultural differences and adapt therapy accordingly. Across the quotes, there is an unquestioned notion that cultural differences do exist, are relevant to the ED and useful to consider. This idea of cultural difference plays out in so many ways and has many repercussions in terms of therapy. However, therapists' ideas of what cultural difference means are based on various notions that may not be linked to what their SUs tell them. As such, whether differences

are approached with a curious stance or challenged, is dependent on participants interpretations.

Rua referred to going beyond the idea of having an 'expert position' instead of advocating learning from the SU:

"I think we just have to kind of, go beyond our knowledge, we sometimes have to approach that with curiosity about things about understanding and about taking that into consideration. It's a tricky balance though because we don't want to do it in a in a routine fashion." (Rua, Line 498-501)

In Rua's extract, she describes approaching therapy with curiosity suggesting going into the unknown without formal guidance. She describes a 'tricky balance' suggesting a process that is tentative and adjusted.

In the following comment, Avery designates a category to 'these families':

"I also think we can learn from these families and then we can then adapt how we use the NICE recommended treatment with other families from similar or different backgrounds because you kind of realise that, you know, if you talk about food in that way, or if you talk about, body image is a really good one, because what's acceptable and revered does differ across cultures." (Avery, Line 239-243)

Avery places the agency and expert status (as discussed in relation to Rua's approach) with families, rather than assuming it for herself, in her reference to learning from families. She discusses this apparent openness concerning the issues of the NICE guidelines. However her discussion of body image preference appears to be theoretical and not necessarily based on what has been said by FDEDs in therapy.

Amaya referred to using curiosity, but this was nuanced since she feels she might have more permission to be curious about a client's culture given her ethnic minority status:

"I don't necessarily think there's more awareness or sensitivity, what I think is that I feel, and it might just be me that I have more permission, I have... It's easier for me to ask, because I'm a minority as well, even though I might not be the same minority." (Amaya, Line 173-175).

Nevertheless, she was keen to state that this did not make her more 'sensitive' than White therapists. She described using the notion of shared identity and the experience of being an ethnic minority to navigate therapy with her SUs - even if the specific cultural nuances were thought to be different.

3.4.3 Theme 3: Therapists Feeling Restricted

All participants described a sense of restriction in their clinical work with ethnic minorities and a desire to adapt and tailor work for this group effectively. Although this content involves issues generated by the theme 'working with cultural difference' the aspects of restriction were strong and particular enough that it felt important to develop them into a distinct theme. Restrictions were perceived to arise from structures such as the NICE guidelines and impositions by service management. Participants also reported limited amounts of clinical time and training dedicated to cultural factors. Lastly, there was a fear of being culturally offensive or doing something wrong. These sub-themes are described in the following sections.

3.4.3.1 Subtheme 1: Wanting to offer diverse therapy

Participants expressed a keen desire to offer a broader range of therapeutic models or adaptations to suit the needs of their ethnic minority SUs. For example, Cyra suggested a split between the service managers at the top and therapists at the bottom:

"So, the people that were at the bottom doing the actual clinical work wanted diversity. They wanted to use different models. But I think it was coming from top-down, less of the clinical staff much more of the management team. And I think it's just it's just politics. It's just people who make those guidelines, erm, kind of enforcing kind of..." (Cyra, Line 315-319)

She referred to the management team and the NICE guidelines and suggested a collusion due to politics. In this extract, in using the word 'enforcing,' Cyra implies feelings of oppression and a sense of infighting related to the service management. This group, she feels, have strict rules about what therapies are offered by therapists. This conflicts with what she deems to be the ethos of the therapists themselves, i.e. to offer an integrative and diverse range of approaches.

Dominic's comments were similar to Cyra's:

"I can see that it's not helpful for you. So let's try something else because it seems like you have to get the stamp of approval from people actually, don't actually know the person because they've never seen her, just heard me talking about this person." (Dominic, Line 239-241)

He referred to an external power that monitored his work, only allowing him to do particular approved therapy. In this extract, he describes a close nurturing relationship with his SU. He wants to help but is restricted by the management, who are external to this therapeutic relationship and have to judge and approve his decisions. His words suggest a feeling of intrusion into the close relationship he has with his SU, and he appears to feel annoyed by this.

It is noted that in Cyra and Dominic's scenario, only the therapists' perspective is presented. From another perspective, it is noted that two participants who were in both managerial and therapeutic roles insisted that flexibility existed:

"...some of the families I've worked with have found it very unusual to bring food in and for the, for me as the clinician or whoever's co-working not to eat. You know, families have talked sometimes about feeling that's a bit uncomfortable or disrespectful. So, we adapted this to join them and eat the food." (Jessica, Line 225-229)

In the previous extract, Jessica, who is involved in both management and therapy, tells us about a practice that has been adapted. It is a contrast to Cyra and Dominic

who experience a lack of flexibility. Cyra and Dominic speak largely as 'I' whereas Jessica uses 'we' implying a team. Jessica describes 'joining with the family' as a departure from the NICE guidelines favouring the perspective of the SU. This implies supporting the empowerment of the SU.

3.4.3.2 Subtheme 2: No time to reflect

Participants suggested that the desire to provide cultural adaptations was further restricted by time constraints. There was often not enough time to reflect on clinical work or learn how it could be adapted. Reflection is considered to be a crucial element of psychological practice. However, in the context of busy caseloads, this fundamental practice was felt not to be prioritised.

Katherine explained how reflection on culture should be interwoven into every aspect of the work:

"I think it needs to be part of, to try and entangle it in all the work that we do. I think like many things, there wasn't always the time to include that thinking. So, I don't think, I don't know if it's like gaps in my knowledge or if it's more like the time to think that might be more of what's missing sometimes." (Katherine, Line 398-402)

Much of a therapist's work requires being able to step back and reflect on what has been said in the session. However, Katherine describes not even having time to think. This implies a sense of exhaustion and feeling unsupported. Katherine seems unsure about whether cultural adaptations are given enough time and appears to implicate both time and gaps in her knowledge.

Avery explained that she wanted to see the provision of ongoing training that encouraged reflection to develop awareness:

"I think the other one would be just ongoing training for staff to increase awareness, to help people to reflect on their context versus other people's context, and to think about similarities, differences and sort of reflect on that." (Avery, Line 542-543)

This included going beyond and considering 'context'. In her comments here, she expresses a genuine desire to learn and receive training. Participants expressed a desire for first-hand experience with ethnic minorities to facilitate their knowledge and learning:

"...but if we were to develop an outreach service and actually have the time to go into people's homes and get used to how they live their lives, but that would help in general and getting to know how people from different minority backgrounds live their lives in their homes." (Mary, Line 339-342)

Mary explained that she would like the time to visit SUs in their home to learn about their context. She felt this might bridge the gap between inpatient and community services. In her comments, she is aware that the way an SU presents in the clinic might be different to what happens in their home surroundings. This also implies that Mary feels she might find answers on how to approach the work with her SUs if she can observe their natural familial and home context. She notices that she does not know everything but is willing to learn.

3.4.3.3 Subtheme 3: Fear of getting it wrong

Participants explained that they were keen to address differences but sometimes worried about making incorrect assumptions about a client's culture or saying something offensive:

"I think I have become a lot more confident at just um, being quite I used to be quite nervous about saying anything about culture in case someone thought I was being offensive or if someone thought I was putting up a barrier between us..." (Beth, Line 119-121)

Beth describes a nervousness that existed more in the past. In her extract, she explains how she feared to endanger the therapeutic alliance by saying something unintentionally offensive and creating a 'barrier'. However, in the present, she describes an increasing confidence with the issue.

As seen in Katrina's quote to follow, this has subtle nuances:

"But I also, I guess, one of the things that I have to be mindful of is I'm a White woman, and I've been working with somebody who may not come from the same background and make assumptions about me and what I think about them." (Katrina, Line 384-389)

Therefore, intertwined with the fear of getting it wrong is being mindful of how they are perceived by SUs. Katrina identifies the visible characteristics of her gender and ethnicity as aspects that the SU might initially judge. As such, she is mentalising and considering the SUs experience in their relationship. She ensures she is aware of this throughout.

Fear was not just experienced when addressing culture with clients. The fear appeared present in the extended system of SEDS:

"I think people get really defensive. And that's not necessarily what they're trying to say, I certainly wasn't saying that just because we're not adapting treatments it's racist." (Sachi, Line 539-541)

Sachi explained that she was fearful of mentioning the need to consider culture in therapy in multidisciplinary meetings in case this was seen as critical of the service. Although in this extract, Sachi sees herself as part of the team using the term 'we're'. However, she also sees herself as separate from 'people' who 'get really defensive'. Sachi explains she perceived defensiveness from others when she proposed addressing culture and that she felt her comments were interpreted as criticism or 'racism' towards the system. This, in turn, implies anxiety within the team system.

There was also a fear of raising cultural adaptations in supervision. Cyra, who is from an ethnic minority background, explained that all of her supervisors were White:

"In fact, when I present an ethnic minority case, if I, I feel like in supervision, if I constantly emphasise their ethnicity, I feel like I'm blowing it out of proportion. It almost feels like I'm deviating away from the model and kind of doing something I shouldn't be doing." (Cyra, Line 390-394)

This amplified her fear of considering cultural adaptations in supervision. In the above extract, she says 'I shouldn't be doing', suggesting she doubts herself and her motives and whether she is right. Furthermore, she refers to 'blowing out of proportion', which implies a sense of irrationality. In these words, she juxtaposes herself as irrational alongside the evidence-based model.

4 DISCUSSION

4.1 Chapter Overview

At present EDs are addressed by specialist tier 2 and 3 mental health services. EDs require special attention in part due to the poor physical and long-term psychological outcomes and associated high mortality rates (Fichter & Quadflieg, 2016; Fichter et al., 2017; Quadflieg & Fichter, 2019). However, one of the few and most recent reviews of its kind suggested that individuals from ethnic minority backgrounds are less likely to receive a diagnosis, referral, or treatment, for an ED (Sinha & Warfa, 2013). The objective of this thesis was to explore therapists' perceptions of working with ethnic minority FDEDs and cultural concepts in terms of what it means to the therapists themselves and how this influences thier work. Overall, it is hoped the findings will improve access and treatment for ethnic minority FDEDs.

In the following sections, the main findings will be explored in the context of the broader evidence base (presented in the literature review section 1.7 and 1.8). Thereafter, the implications of these findings for SEDS working with ethnic minority FDEDs, and suggestions for future research are discussed. Subsequently, the strengths and limitations of the thesis are evaluated, and reflexivity is revisited. The chapter ends with a concluding statement

4.2 Summary Of Findings

The first research question was:

'What are therapists' perspectives of how ethnic minority females diagnosed with eating disorders access SEDS?'.

The second research question aimed to hear:

'What are therapists' experiences of working with ethnic minority females diagnosed with eating disorders in SEDS?'.

The themes were as follows:

Table 3: Overarching themes and subthemes

Overarching theme	Sub-theme
Notions of shame as barrier	Reduced family support
	Shame in saying it to therapists
	Perception of differing view of EDs
Working with 'cultural difference'	Understanding different functions of an ED
	Addressing acculturation
	Using curiosity
Therapists feeling restricted	Want to offer diverse treatment
	No time to reflect
	Fear of getting it wrong

4.3 Theme 1: Notions Of Shame As A Barrier

Participants reported a belief that *shame* impacted how FDEDs used therapy or accessed treatment. The words stigma and shame were used interchangeably. Goffman defined stigma as a situation that excludes an individual from being fully socially accepted (Goffman, 1963). The present finding from the participants complements findings by three other studies of South Asians themselves and FDEDs, which also suggest that shame is a barrier for ethnic minorities accessing treatment (Channa et al., 2019; Chowbey et al., 2012; Wales et al., 2017). However in the present study participants had different concepts of shame and how it works in other cultures, and this appeared to influence their therapeutic work. This included not challenging shame, or assuming EDs in certain cultures are taboo and linking this to a negative interpretation of parents. In the following sections, the sub-themes are discussed.

4.3.1 Reduced Family Support

Family involvement and support are recommended as an important part of recovery (NICE, 2017). Participants communicated the perception that ethnic minorities have less family to support them with therapy and recovery. This manifests in two forms. Firstly, it was felt that FDEDs wanted to exclude family members from knowing about

the ED and therapy sessions due to their sense of shame. Secondly, it was thought that families wanted to absolve themselves of responsibility for the ED that they felt to be shameful. This interpretation influenced how therapists worked with this group, often in the form of colluding with the SU to exclude parents – with therapists thinking that a lack of disclosure was due to shame and casting blame to parents and their culture for the ED being a taboo and lack of involvement. Whilst in some cases there may be some substance to these beliefs, therapists' ideas can themselves become barriers or otherwise prohibitive.

In the field of EDs, research has suggested that parents often fear blame (Stillar et al., 2016). Previous research indicates that families may also avoid the community or extended family for fear of stigmatising comments about their child (Chowbey et al., 2012). This fear of blame and shame may be experienced by therapists through transference (Gelso & Hayes, 1998). Such emotions could make it difficult for therapists to approach the topic of how to include parents in FBT without implying blame. This fear may also act as an indirect barrier and reduce family support.

In the literature, several other explanations have been put forward to explain reduced family support outside of the attribution of shame which the participants in the present study noted. These include pre-existing family dynamics such as low paternal affection or gendered domestic roles, both of which are thought to contribute to psychological distress fuelling the ED (Treasure, 2018). Another explanation is that parents who are of an ethnic minority have an alternative approach to caring for their child, which therapists interpret as the product of shame. In this study, participants acknowledged that some ethnic minority groups indeed originate from collectivistic societies in which there may be more emphasis upon getting help from the family or immediate community before going to external services. This tendency is documented in the literature (Wales et al., 2017).

Furthermore, behaviour which is deemed by a parent to be caring is also very much subject to interpretation from the therapist's cultural viewpoint. As previously mentioned in the Introduction (section 1.8.2), research has suggested that ethnic minority parents are perceived to be less warm and more critical than White parents (Hoste & le Grange, 2008). This perception may be culturally biased, as research

suggests that the accuracy of emotion recognition is reduced when interpreting people from a different culture (Wickline et al., 2009).

4.3.2 Shame In Saying It To Therapists

Participants felt that ethnic minority FDEDs and their families avoided or minimised eating difficulties and weight and shape concern in favour of the expression of physical symptoms. Participants questioned whether experiences of shame may impact how EDs are communicated by FDEDs. Topics around the body are known to be a source of shame which increases the risk of developing an ED (Cella, Lannaccone, & Cotrufo, 2019). Indeed participants in the present study observed that it took them longer to discover what was driving the ED for ethnic minority females. Nevertheless this may be equally due to the types of questions that therapists are asking and whether that questioning is relevant to the SUs experience.

Participants felt that families of FDEDs also expressed explanations of EDs, which put forward physical conceptualisations ahead of discourse around psychological distress. Aligned with this is research involving observations from the local South Asian community and therapists combined. This work has suggested that some people in the Asian community look for physical causes, such as a 'thyroid disorder', to explain the weight changes seen in EDs (Wales et al., 2017). Participants suggested that this different emphasis led to a delayed presentation to SEDS. They felt that in such cases, GPs might rule out the presence of an ED in the face of complaints of stomach discomfort or amenorrhoea and instead refer individuals to gastroenterology or gynaecology. This would inevitably create a more complex pathway to SEDS and delay referral. A complex pathway is noted for ethnic minorities in general when accessing mental health services (Bhui et al., 2003).

The assumption that shame led to a different expression of psychological distress for EDs is just one explanation. It is unclear whether physical complaints are due to shame as some participants hypothesised, or due to a different way of communicating. There is some evidence in the literature which compliments the latter explanation. Research into Vietnamese SUs with depression has suggested that they were more likely to somatise if they had language difficulties (Dreher et al., 2017).

Another possibility is that ethnic minority FDEDs do experience gastro-intestinal discomfort and that the reason for this may be more complicated than a simple desire to avoid discussing psychological factors. Indeed gastro-intestinal discomfort often occurs with severe starvation or irregular eating. The DSM-5 has acknowledged that gastro-intestinal discomfort could be a warning sign of an ED more commonly in Asian cultures (American Psychiatric Association, 2013). In line with this, in the 1800s, EDs were conceptualised as a form of hypochondria, thought to be caused by a lack of appetite. Only more recently has there been a focus on weight and shape disatisfaction as proposed by the sociocultural model of EDs (Keel & Klump, 2003).

Despite the possibility that ethnic minorities may be more likely to focus on physical symptoms, categories such as non-fat phobic anorexia do not feature in the DSM-5 or ICD-10 diagnostic criteria. Therefore, it is not as widely known about by services and not commonly addressed in treatment. This has potentially damaging and detrimental implications for both FDEDs and therapists.

4.3.3 Perception Of Differing Views Of Eating Disorders

Participants explained that they perceived EDs to be conceptualised differently by ethnic minority FDEDs. It has been argued that to understand EDs and generate better therapeutic outcomes, the complexity of culture should be considered. This would involve consideration of contextual influences such as traditions, beliefs, and religion (Channa et al., 2019). The present participants felt that EDs had the potential to socially ostracise members of minority groups. They suggested that this had long-term implications for the individual's future. Indeed, previous research into South Asians diagnosed with EDs has indicated that shame associated with an ED can lead to further isolation (Channa et al., 2019).

Participants also suggested that the 'differing view' of EDs which they understood such groups to hold (and which increased associated shame), might be due to differences in education, 'reduced awareness' or a non-western way of understanding distress. For example, two therapists made references to FDEDs and their families understanding the ED to be caused by gin - a form of spiritual possession. In such

cases, FDEDs might be expressing psychological distress in a form which has meaning for them in the (non-western) context in which it was generated (Bentall & Pilgrim, 1999). This interpretation is aligned with research of particular cultures, which suggests the onus is placed on the individual to recover by using methods such as prayer. The ED, in such a context, is thus associated with shame and stigma (Channa et al., 2019).

Similarly, findings in North Africa have indicated that people diagnosed with schizophrenia are held responsible for their illness, and this is fuelled by shame (Angermeyer et al., 2016). Such contexts, as suggested by (Nieweglowski, Qin, Paniagua, & Corrigan, 2020) may, in turn, explain the pessimism and unwillingness towards recovery which the therapists reported noticing in their clients. Therapists confronted with such ideas without an appreciation for their context might perceive them to reflect a 'reduced awareness'. This is perhaps dismissive of ways of experiencing psychological distress that exist outside of, more familiar, western modes of understanding.

To add further complexity, the idea of 'differences in understanding' may itself take different forms. Participants suggested that a child and their parents might also have different understandings of the ED. They identified differences in language and country of education as potentially leading to these 'different understandings' of mental health. This echoes the findings by (Chowbey et al., 2012). Nevertheless, it is important to caution against a focus on this without also acknowledging the role of differences in understandings between therapists and the ethnic minority FDEDs they provide therapy for.

4.4 Theme 2: Working With 'Cultural Difference'

Participants suggested that in ethnic minority FDEDs, features of the ED had different functions. This was described as a 'challenge' since these features did not map onto the diagnostic or therapy models to which they were accustomed. This 'challenge' can be understood in different ways. Though the therapists tended to emphasise the way the FDEDs presented, the challenge might also be attributed to the therapeutic models to which they were beholden. Such models may be too narrowly focused on ED

features such as weight and shape concern, as opposed to the broader context in which the distress is generated. These findings are consistent with observations by Becker (2007) who reported that most research into the presentation and treatment of EDs has been conducted in White FDEDs, and so overlooks non-western ED presentations. This narrow interpretation of EDs acts as a barrier for ethnic minorities to access SEDS and influences how therapists and ethnic minorities FDEDs experience therapy.

4.4.1 Understanding Different Functions Of The Eating Disorder

Participants perceived the causes of EDs to focus on areas outside of weight and shape concern. Interestingly, participants suggested that they were more likely to see ethnic minorities where the EDs were driven by emotional distress (as opposed to by weight and shape concerns). This distress was thought to be a response to their immediate surroundings and interpersonal settings, or family dynamics. Research has complemented their observations suggesting that traumatic experiences are more common in ethnic minorities and that the associated psychological distress fuels the ED (Gentile, Raghavan, Rajah, & Gates, 2007; Lacey & Dolan, 1988). Indeed, this might also reflect a bias at referral whereby individuals from ethnic minorities are required to reach a higher clinical threshold before being referred (Ratan et al., 1998; Waller et al., 2009).

In practice, the distinction between weight and shape concern and emotional distress is perhaps not as distinct as the participants propose. For example, it is unlikely that weight and shape concern is possible without causing emotional distress.

Furthermore, most who are referred to SEDs, regardless of ethnicity, are likely to be in emotional distress and this has instigated the referral. As such participants might be interpreting increased emotional distress and trauma as a racial difference, as opposed to questioning the concept of weight and shape concern itself. For example, the high focus on 'weight and shape concern' by one of the most recommended therapies for EDs, that is the CBT-E model, may subtly exclude those FDEDs who present with different ED causes, such as interpersonal or emotional factors (Fairburn, 2008; Fardouly, Willburger, & Vartanian, 2018). Without questioning therapists notion that patients who are ethnic minorities are more likely to be

emotionally distressed or traumatised due to family dynamics, we may be seen to be pejorative or assuming about the way these FDEDs and their families are. Tangentially this suggestion is linked with other research which found mental health services perception of Black people with mental health problems, to be fuelled by prejudice and misconceptions and this led to restrictive interventions (Keating & Robertson, 2004).

4.4.2 Levels Of Acculturation

The participants recognised acculturation as a specific risk factor for the ethnic minorities they worked with. A systematic review supports that culture change is associated with more significant ED distress (Doris et al., 2015). Participants in the present study indicated that acculturation necessitated the individual to balance contrasting needs - citing cultural expectations such as different foods and body shape ideals, caring for family, family dynamics and religious obligations, in comparison with the values of western life. In parallel to this observation is research in the US, where therapists have observed how EDs and attainment of the western body ideal may be used by ethnic minorities as a means of assimilating to Western culture and attempting to achieve acceptance (Smart et al., 2011). It may be suggested that some participants connection between wanting to attain the western body ideal for acceptance and the development of EDs is perhaps simplistic and assumes that this concept has a universal meaning for everyone. This might reveal how some therapists' approach this in therapy. Furthermore, some participants highlighting the impact of body ideals on ED development might be said to conflict with the prior sub-theme that ethnic minorities are less likely to present with weight and shape concerns.

Nevertheless, other participants in the present study did acknowledge how acculturation may have differing levels and meanings. For example, it was noticed how some in African Caribbean cultures might have a preference for larger body types. This observation complements previous research which suggests that valued body ideals can often differ between races (Overstreet, Quinn, & Agocha, 2010). This US study showed that overall women preferred a curvaceous body type; however, Black women preferred their body ideal to be larger in comparison to White

women who wanted this ideal to be slimmer. Discrepancy between the individual's body shape from their valued body ideal, predicted levels of body dissatisfaction (Overstreet et al., 2010).

Furthermore, participants proposed that acculturation levels might differ with young people being more strongly influenced. Indeed ethnicity is complex, and this has been echoed in the literature. According to Duncan & Trejo (2017), ethnicity is an identity which has a different meaning to every individual within that ethnic group (Duncan & Trejo, 2017). Ethnicity has different levels and can range from the first, second and third generation. It is proposed that families who have migrated are at a relative disadvantage, having lost their social networks and extended families to assist them and as such may, for example, lack knowledge of the mental health services and support that exists (McDonald & Steel, 1991).

4.4.3 Using Curiosity

Participants reported using curiosity to guide their therapeutic work and tailor to cultural differences. By using curiosity, they referred to learning from the SU as opposed to upholding the 'expert' position. The idea of using curiosity is in line with Milan systemic therapy models (Ceccin, 1992). However, the present research revealed a duality between the notions of using 'curiosity' and feeling 'uncertain'. This is because participants reported using curiosity in cases where they felt uncertain or did not understand cultural differences. This may be viewed as parallel to the concept of *cultural humility* which has been cited in the literature. Here it is acknowledged that a person does not know everything about cultures other than their own. As such learning is treated as a lifelong process that entails a humble approach which is open to challenging cultural biases (Foronda, Baptiste, Reinholdt, & Ousman, 2016).

Nevertheless, the concept of cultural humility may not fully incorporate therapists personal interpretation of cultural difference. Similarly, participants in the present study did not acknowledge that whether a behaviour was approached with curiosity or challenged, appeared to be very much dependent on their interpretation of the behaviour. For example, whether a therapist accepts an FDAN fasting as due to

religious reasons; or whether the therapist decides to challenge this behaviour and interprets her fasting as part of the ED is dependent on the therapists judgement.

It may be argued that participants lack of certainty regarding working with someone from a different culture generates a somewhat vague catch-all notion of being 'curious'. This weakness is not explicitly accounted for by the cultural humility model by Foronda and colleagues (2016). Indeed beneath the term, 'curiosity' participants expressed little about what they noticed when they did use curiosity or how they used the information. This perhaps suggests uncertainty regarding how to apply what they found using curiosity to their work with the SU.

As a counter-perspective, it may be argued 'using curiosity' locates the responsibility to explain cultural issues with the ethnic minority FDEDs. This approach perhaps is used to quell the fear of participants uncertainty. This presents counter-posing perspectives - one which empowers the SU and another that places the responsibility on the SU. FDEDs are likely to be in psychological distress, some of which might be linked to difficulties in acculturation. Given this, it is perhaps insensitive to assign this responsibility to them. In turn, a commitment could be made to learn together, allowing a shared responsibility between therapists and SU (Wood & Patel, 2017).

4.5 Theme 3: Therapists Feeling Restricted

Participants reported feeling restricted when working with ethnic minority FDEDs. This theme refers to anxiety about getting cultural adaptations wrong, notions of wanting to offer more diverse and flexible therapy and wanting more time to adapt and reflect on culture. It is argued that there is a conflict between participants wanting more flexibility but also fearing they might get it wrong when veering away from the protocol.

4.5.1 Want To Offer More Diverse Therapy

Participants expressed a feeling of being restricted in what they could offer ethnic minority SUs. They questioned the NICE guidelines recommendation of therapies with the lack of established outcomes specifically for ethnic minorities. A consistent theme was the Euro-centric nature of the research upon which the NICE guidelines

were based and whether such guidelines could be applied appropriately to ethnic minorities. It was felt that service management wanted a more strict deliverance of NICE guidance treatment. Nevertheless, this notion contrasts with NICE practical guidelines for EDs, which emphasise the use of subjective judgement when applying the guidelines (Wilson & Shafran, 2005). In comparison to participants idea of services, participants themselves insisted they wanted to have the flexibility to deliver a broader range of interventions that could address cultural nuances and complexities. An additional conflict appeared whereby therapists who were also in managerial roles insisted that there was ample opportunity for cultural adaptations and flexibility in what was offered.

It has been argued that working with the physical risk in EDs adds anxiety to the therapeutic work for therapists (Dodge, 2019). The feature of cultural difference may add to this anxiety and uncertainty. As such, unconscious collective ego defences may form to protect against the anxiety of this work (Menzies-Lyth, 1988). These defences might be locked into the institution and include the requirement that therapists deliver highly manualised and evidence-based therapies (such as CBT and FBT) with less room for error. Nevertheless given that these models are based on western styles of thinking, they may act to reduce a therapist's ability to flexibly address problems and learn about ethnic minority FDEDs (Menzies-Lyth, 1988; Pope & Burnes, 2013). As such, therapists may also feel restricted by these guidelines and desire more flexibility and creativity. Therefore, the sense of restriction may not only originate from services, but also participants' anxiety about addressing cultural difference. It has been acknowledged that insufficient knowledge may also be a barrier to therapists adapting therapy protocols (McEvoy et al., 2017).

4.5.2 Not Enough Time To Reflect

Participants reported feeling restricted by a lack of time to reflect on cultural issues. Indeed, the sensation of lack of time may be partially aligned with a belief that mental health services are subject to systematic under-funding, in comparison to services addressing physical health (Trade Union Congress, 2018). Culturally sensitive provision requires more time and consideration of how to address barriers such as language difference, use of interpreters, increased awareness and working with discrimination (Bignall et al., 2019). Importantly participants referred to both lack of

time and gaps in knowledge. This was often coupled with an implication of feeling exhausted and unsupported.

As mentioned in the previous theme (4.5.1), there is a notable conflict between the views of management and therapists on whether there was time and permission to address cultural issues. Ideas by Menzies-Lyth (1988) may partially explain the aforementioned conflict - in the form of avoidance of approaching reflection on culture as a defence against the anxiety and uncertainty of this work. Anxiety may be fuelled by reduced knowledge without a supporting evidence base that may hinder cultural adaptions of therapy (McEvoy et al., 2017).

Within this theme, there was the expressed desire for ongoing training on cultural issue to be provided by SUs. Such an approach may help to mitigate the problems of 'them and us thinking' and also ensure professionals 'remain human' in their approach (Lea, Holttum, Cooke, & Riley, 2016). Nevertheless, as mentioned before, such work should be approached collaboratively without placing an unfair onus on the SU to educate therapists.

Participants also suggested the potential value of being able to visit SUs in their homes for the family meal and to use this to understand their context. At present, home visits are not commonly allowed at SEDS due to issues of cost-effectiveness and perhaps safety (and effectively being unlawful at the time of writing under present Covid 19 restrictions). However, this approach could help to work with the broader context of wider social issues and inequalities and individual meanings as opposed to adopting a narrow focus on, for example, cognitions (Johnstone & Boyle, 2018).

4.5.3 Fear Of Getting It Wrong

The theme itself was quite diverse with fears playing out in a range of ways. Firstly, fear played out on a personal or human level in worry of saying something unintentionally offensive about the SUs culture and creating a 'barrier' in therapy. Aligned with this, is previous research which found that European American therapists were less likely than African American therapists to raise the topic of race

if the SU did not raise it themselves (Knox, Burkard, Johnson, Suzuki, & Ponterotto, 2003). It was thought that discomfort with the topic might be related to European American therapists being less likely than African American therapists to have their own negative lived experiences related to race (Knox et al., 2003). Indeed, lived experience can perhaps increase confidence and reduce fear around discussing the topic.

Furthermore, some White British participants cited an awareness of how their race, or 'Whiteness' might be viewed by ethnic minority FDEDS. Similarly, research has cited how working with someone of a different ethnicity may make the therapist more aware of their race, differences, or privilege (Knox et al., 2003). This realisation of difference may heighten the fear of getting it wrong.

Secondly, there was the fear about getting cultural adaptations wrong and overstating its necessity. There was a fear of being judged by other team members for wanting or suggesting cultural adaptations. Without an established evidence base for therapies demonstrated in ethnic minorities, the responsibility falls to the therapist to devise any necessary adaptations. Adapting therapries such as CBT-E or FBT based on the therapist's interpretation and intuition can inevitably feel uncertain and tentative (Eisler, Simic, Blessitt, et al., 2016; Fairburn, 2008). Furthermore, there may be a power differential between therapists and these widely upheld therapy models, which silences the therapists desire to adapt (NICE, 2017).

The sensitivity and complexity of adapting therapy models should not be underestimated. Neither can it be assumed, without an evidence base to work from, that it can be done quickly. In the field of 'psychosis', a culturally sensitive adaptation of CBT demonstrated the high level of input and consideration needed (Rathod, Kingdon, Phiri, & Gobbi, 2010). This adaptation was derived by gaining views from SUs with a diagnosis of 'schizophrenia', lay members from ethnic minority groups, CBT therapists and mental health practitioners. This work led to ideas for sensitive adaptation such as incorporating culturally-based patient health beliefs, attention to help-seeking pathways and other technical adjustments (Rathod et al., 2010).

Also relevant here is the data from the pre-study questionnaire whereby participants reported their confidence in working with ethnic minorities. Their scores ranged from 5 to 8 out of 10 (median: 8) and this did not seem to increase with the number of years having worked with EDs. This rating may be viewed as relatively high. Nevertheless, this finding contradicts what appeared to be said in the interviews whereby there was a fear of saying something culturally offensive or doing something wrong. As such there was the sense that their work was approached tentatively. This finding could indicate that both of these terms (i.e. having confidence or fear of getting it wrong) have slightly different meanings, or an unwillingness to admit not having confidence for fear of appearing unable to do this type of therapy. This issue of having confidence or having fear is an important one since it could be argued that confidence is needed to ask SUs questions about their ethnicity, culture or experience of racism, whilst taking the risk of making mistakes, to assist providing cultural adaptations to CBT or FBT therapy models (Naz, Gregory, & Bahu, 2019).

Confidence could have an impact on the therapeutic alliance and experience of therapy for ethnic minorities. Indeed recent research has suggested that therapists who were externally rated as displaying racial and ethnic comfort when working with ethnic minority SUs were better able to retain them in therapy and therefore not have premature termination of therapy (Owen et al., 2017). The authors hypothesised that these therapists were able to create a sense of safety for the SUs which resulted in better retention rates (Owen et al., 2017). As such, by proxy, these findings suggest that reducing the feeling of fear of doing something wrong in therapists will increase the sense of SUs safety in the therapeutic relationship and hence lead to better outcomes for the SU. Such positive experiences with SEDs might also break down wider the barriers of seeking help in the community (Naz et al., 2019). The implications for this will be discussed further in section 4.6.

4.6 Implications And Recommendations

The following section provides suggested recommendations based on the findings.

The recommendations have remained cognisant of the approach referred to by Rua

(see below) to ensure people are treated as individuals. If we routinely treat someone differently based on their race, we risk falling back into historical notions of difference. As such a tentative approach is adopted, given that these suggestions are based on a relatively small sample size.

"I think we just have to kind of, go beyond our knowledge, we sometimes have to approach that with curiosity about things about understanding and about taking that into consideration. It's a tricky balance though because we don't want to do it in a in a routine fashion." (Rua, Line 498-501)

4.6.1 Service Level

This section focuses on encouraging therapists and SEDs to consider new ways of thinking and challenging concepts we may take for granted.

4.6.1.1 Start of therapy

Participants referred to shame as a barrier to therapy and help-seeking. To encourage family involvement, therapists may want to give special attention in two phases. There should be consideration of inclusion of family that might exist in intergenerational households for some select sessions. Inclusion might be encouraged by the use of cultural genograms at the start of therapy (Hardy & Laszloffy, 1995). This may also help therapists understand the dynamics in larger extended families and the effects of migration through the generations (Hardy & Laszloffy, 1995). Services and therapists may also want to consider differing cultural scripts around EDs. This may help to ensure that information about EDs is communicated to the FDED and their family in a way that does not reinforce blame or shame (Castro-Vázquez, 2019). This will inevitably prompt therapists to ask questions about race, ethnicity and even experiences of racism and may increase confidence in adapting and delivering culturally competent therapy going forwards (Naz et al., 2019).

4.6.1.2 Reflective practice on culture

It is proposed that measures should be taken to support therapists in their work. With an added layer of intersectionality, that is a cultural difference, this work with FDEDs may at times feel overwhelming (Crenshaw, 1989). These sources of anxiety may reduce creativity and flexibility in considering and providing cultural adaptations for ethnic minority FDEDs (Dodge, 2019). As such, therapists must be given the time and space to consider cultural discourse in supervision and with their colleagues in regular reflective practice that focuses on culture.

Such spaces might have the effect of increasing therapist confidence and reducing the fear of approaching this topic, thereby facilitating cultural competency and nurturing a safer therapeutic partnership with the SU (Naz et al., 2019; Owen et al., 2017). The ethos of these working environments could move to provide containment and a curious and non-judgemental stance where questions can be flexibly discussed. This could involve group thinking about how to approach the family meal as part of the FBT model while considering cultural scripts to encourage cultural sensitivity (Eisler, Simic, Blessitt, et al., 2016). Specifically, the technique of coordinated management of meaning could be adopted to explore different cultural scripts around mealtimes (Bruss et al., 2005; Cronen & Pearce, 1982). This could give therapists the time to consider their SUs beliefs about food, how food is served, the meaning of food at religious festivals, emotions associated with food, how food is understood by FDEDs or their parents and the implications if they have experienced hunger or famine (Bruss et al., 2005; Chowbey et al., 2012; Cronen & Pearce, 1982; Wales et al., 2017). Reflective practice could also focus on one's own ethnic identity and how this interacts in the therapeutic relationship (Rothman, Malott, & Paone, 2012). This awareness of difference or similarity is something that participants in the present study broached.

Reflective practice must be set up so that it focuses on issues such as culture, race, ethnicity and cultural scripts and how this may playout for the ED. This focus will ensure the topic is discussed and not avoided. Making an effort to increase the cultural diversity of therapists in SEDS teams might also increase the possibility of this topic remaining on the agenda and allow for discussion of lived negative experiences concerning race in FDEDs (Knox et al., 2003).

4.6.1.3 Addressing hierarchy in teams

Therapists reported experiencing a struggle between the models and guidelines they are required to use by management and wanting to make adaptations but in an individual flexible form. Nevertheless, some therapists who were also managers dealt with this issue differently. Steps could be taken to reduce the sense of hierarchy and imposition by management that is felt by some therapists. This could focus on management encouraging therapists to feel more comfortable in their therapeutic work and actively encouraging them to be thinking creatively and adaptive to address cultural difference.

Ideally, such a space would promote shared responsibility within teams, as opposed to feeling that clinical decisions on patient care are assigned to management only (Slade, 2017). The justification for this is that it leads to better clinical outcomes and is a right for those in the team. Monthly meetings could be held focusing on how the team is run and managed and how clinical decisions are made regarding SUs therapy. This would allow all members including management, therapists, assistant psychologists and even administrators to contribute and have their say. All of these people have valuable insights into that path that SUs take from referral, during therapy to discharge. Importantly the topic of choice should be assigned to a different member of the team, regardless of role or experience, who will chair the meeting on a rotating basis. This will allow for more diversity in decision making.

4.6.1.1 Co-production and training for therapists

Participants expressed a desire for ongoing training on culture and this to be coproduced with SUs. Nevertheless, FDEDS should not be placed into a position where they are required to educate therapists and, instead, a collaborative approach should be adopted. Boyle and Harris, (2009) have defined co-production to mean: "delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change." (p.11) (Boyle & Harris, 2009).

At present, many NHS mental health services have SU involvement. However, SU involvement that specifically addresses training for cultural issues in therapy is not systematically implemented. The demographic of the local area in which the SEDs is located could be used to inform relevant cultural training towards the SUs in the catchment area and who may require support at the service. SUs who have recovered from the ED may want to contribute to this training. Indeed SUs who have recovered and their families are already involved in presenting their story to those currently suffering with an ED, as part of Multi-Family Therapy Groups, so such involvement would not be a significant departure from standard practice (Eisler, Simic, Hodsoll, et al., 2016). An additional option could be utilising cultural advocates and ensuring this resource is readily available for therapists. Regular and long-term co-produced training will aim to increase confidence in delivering culturally competent therapy. The effect of training and greater practice-based knowledge will aim to reduce anxiety and thereby reduce the therapists' propensity to avoid instigating discussion of ethnicity, culture and racism in therapy with their SUs (Naz et al., 2019).

4.6.2 Policy Level

4.6.2.1 Patient care pathway

Participants reported observing shame and a difference in the ED features presented when working with ethnic minority SUs. They felt this complicated their route to obtaining a referral to SEDs since their presentation was not instantly recognisable as an ED. Increased awareness may lead to earlier intervention which is associated with better long-term outcomes and a shorter duration of the ED (Brown et al., 2018). As such efforts should be made to support this group with obtaining access to SEDS in a timely manner.

Furthermore, on a national level, SEDs and therapists could be provided with referral guides to support recognition of EDs in ethnic minority groups. This could also be provided in the earlier stages of the referral process, for example to teachers and GPs and be available to families seeking help. Participants mentioned that referrers (such as GPs) did not include detailed information about the SUs that were referred, in terms of their presenting problem, their support system and their route to referral.

Such information could be used to inform the development of these referral guides. The guide should aim to inform health professionals of the broader ED warning signs that may not appear in the ICD-11 diagnostic criteria. These might include menstruating at a severely low weight, non-fat phobic anorexia or the presence of interpersonal and emotional factors as ED drivers. Furthermore, reference could be made to the role of somatic complaints in EDs and encourage offering medical tests to rule out physical causes for loss of appetite alongside referring to SEDs. This might reduce the time and route taken to reach SEDs.

4.6.2.2 Special attention required for Black and East Asian females
Participants reported that South Asians were the most common ethnic minority
FDED to be seen at SEDS. This finding is cautiously treated since it was an
observation without statistical testing. However, this is evidenced by the scoping
review, which found that the majority of UK studies of ethnic minority FDEDs had
been conducted in South Asians living in urban areas (see section 1.8). Moreover,
participants reported more ease with cultural adaptations for ethnic groups that they
had worked with more frequently. Indeed for the vignette interview question: "Say an
ethnic minority (let them name a minority) woman had been referred to you and you
were going to meet her for the first time – what sorts of things would you have in
mind to prepare for the session and make sure it went well?", only one participant did
not choose an ethnic minority from the South Asian population. This is perhaps
surprising given the ethnic demographics of London with Asians making up 18.5%,
Black constituting 13.3% and White British being 44.9% (www.gov.uk, 2018).

As previously mentioned, the suggestion that Black women might have have a preference for larger body types, might cause this group to be overlooked in the field of EDs (research and in clinical settings) (Overstreet et al., 2010). However this group should not be overlooked, since research in the US has shown that the lifetime prevalence of AN and BED does not significantly differ across ethnic groups (i.e. Black, Latino and White) (Marques et al., 2011)

Potentially, a vicious circle exists whereby therapists feel more comfortable working with ethnic minorities that they have had previous experience with. This comfort and

experience may engender a greater understanding of their culture. Other ethnic groups such as Black and East Asian SUs with whom participants appear to have less experience may not benefit from this level of understanding. This may lead to less recognition of their EDs and to difficulties in the therapy itself. These ethnic groups perhaps need special attention through research and audits conducted in local services. Outreach programmes and addressing these groups unmet need may also play an important role.

4.6.3 Future Research

Much of the current evidence base focuses on researching ethnic minority FDEDs perspectives and observing this group. However, key to working with this group is the other half of the picture - that is the therapists they interact with. A research meta-analysis has concluded that a good therapeutic alliance is indeed associated with better patient outcomes (Flückiger, Del Re, Wampold, & Horvath, 2018). Future research could delve further into this area as Knox & colleagues (2003) have done in their research on therapy in the US. Future research could explore ethnic minority and White British therapists experiences of working with FDEDs when there is a racial difference in cross-racial therapy dyads. This could explore the impact of how therapists perceive their therapeutic alliance when working with ethnic minorities and whether they felt it influenced outcomes. The research could also explore SUs and their experiences, which may also shed light on perceived misunderstandings from therapists which may not be readily acknowledged by therapists and the services themselves (Bignall et al., 2019).

The present research revealed that participants felt terms such as acculturation, shame and culture were relevant to their work with ethnic minorities. Nevertheless, these terms had different meanings for the participants. Indeed, these terms, such as culture in the context of EDs may have different meanings or be perceived differently between therapists and SUs. As such research could address the notion of culture itself. It cannot be taken for granted that we know what this means since there is a considerable diversity in how this might be experienced. Another indication would be to explore 'lived culture' or 'lived ethnicity' in the context of EDs from an individual,

experiential and personal approach. This could be acheived by conducting qualitative research with therapists, ethnic minority FDEDs and their families.

Participants have suggested there are alternative ways that EDs present which are not formally acknowledged in current guidelines. In response to this, therapies should be developed through inductive reasoning from inception to respond to the needs of ethnic minorities. This requires an epistemological approach to the research of EDs that is aware of the unequal knowledge production between western and non-western sources (Kubota, 2019). This knowledge should generate therapies which embed our understanding of ED presentation in the context of the broader ethnic group, their race and culture. Therapies could then be developed in a form that it is more relevant to ethnic minorities who do not demonstrate fatphobia or other presentations that have not yet been documented (Gunaratnam, 2003)

4.7 Assessment Of Research Quality

The following sections will evaluate and assess the quality of the research using Yardley's (2000) criteria: sensitivity to context; commitment and rigour; transparency and coherence and impact and importance.

4.7.1 Sensitivity To Context

Issues surrounding ethnicity and race tend to be sensitive (DiAngelo, 2011). Furthermore, the focus on obtaining a therapist's perspective on their work with ethnic minorities may have led to worries about feeling judged or being deemed culturally insensitive. Moreover, I was mindful of my position as an interviewer in the context of being an ethnic minority myself and asking questions about the topic of culture. None of these judgements were the focus of this research. The ethos was always to adopt a collaborative and partnership approach, and this was communicated actively in the information sheet and debriefing. As such, the research was positioned as investigating therapists who are key informants who will be able to offer the breadth of their experiences working with ethnic minority females. Furthermore, the emphasis of the research outcome was placed on leading to

improvements for ethnic minorities, as opposed to judging individual participants responses.

Further details of the contextual consideration for this research are discussed in section 1.9 regarding reflexivity. Throughout the research process, I was aware of how I was investigating a therapist's perspective and was sensitive to how the findings could impact ethnic minority FDEDs. I was mindful I was gathering data representing a particular perspective and treated that as valuable and worth exploring. Nevertheless, I tried to maintain a boundary where, rather than apply my participants' perspectives to ethnic minority FDEDs and draw conclusions about this group on the basis of the participants experiences, I maintained focus on the participants' sense-making and experiences.

Given my proximity to the field of ED and having worked in SEDs in London, the power dynamic between myself and the participants was given special consideration. I was especially aware of how participants might view the confidentiality of their answers. One-quarter of the therapists were people known to me (albeit peripherally) through my work at SEDs. I was mindful of how freely participants felt they could speak. Indeed, there was one occasion when a participant expressed criticism of their service management. Before making this comment, they asked for reassurance that the information was confidential. I expect that the participant was worried that their comment might be disclosed to their service management and affect their employment. This brought awareness of the special care required to ensure all participants and their responses should not be identifiable in the transcriptions or write up. Furthermore, it bought awareness of how this anxiety felt by participants may have influenced or restricted how they responded in the form of social desirability bias.

4.7.2 Commitment And Rigour

Prolonged engagement with the topic was increased through reading the literature and maintaining a critical stance towards the evidence-base. Rigour in conducting the thematic analysis was achieved through supervision and sufficient learning around this technique. Much of the research in EDs has focused on researching FDEDs, and this

pattern of thinking feels natural. However, this research focused on a therapists perspective. A shift in thinking was required to focus on the therapists perspective, namely what it means to the therapists and their experience. Supervision was used to maintain a commitment to this focus and a critical realist stance which assumes there are different perspectives of reality. As such unique insights were generated by a thorough and empathic exploration of the participants' responses. The analysis was completed over five weeks to allow for data immersion.

The research questions were kept in mind, throughout the analysis and write up to ensure a rigorous commitment to the aims. The participants in the present study had sufficient experience and expertise to allow for data saturation, thus allowing a pattern of themes to be derived. Sufficient experience was judged by the inclusion criteria for participants that included having worked in SED for at least one year and having worked with at least two ethnic minority FDEDs.

4.7.3 <u>Transparency And Coherence</u>

Coherence was achieved by ensuring a fit between the research question, the philosophical perspective adopted and the method of analysis. Excerpts of the data were provided to allow the reader to appreciate how patterns in the data were identified. This granted the analysis a good level of transparency. An audit trail of the rules for coding the data was maintained, and this can be observed via the intermediate codes provided in Appendix 10. Two earlier versions of the thematic map are also provided in Appendix 11 and Appendix 12 to depict the process.

Our experience of the world is influenced by our assumptions, intentions and actions, so disclosure of reflexivity, motivations and constraints is equally as crucial as a transparent analytic process. The researcher's influence on the analysis and data is considered in the reflexivity section (section 4.9), and the reflective journal included in Appendix 13. Lastly, the methodology was provided in detail to ensure that each step was outlined transparently.

4.7.4 Impact And Importance

Therapists are a crucial part of the therapeutic alliance and the experience of therapy for FDEDs. Dodge (2019) has previously theorised that in therapy for EDs, anxiety associated with uncertainty can hinder therapists' to address cultural differences. At present, however, the experience of therapists are overlooked by the evidence base, and the current focus is very much on FDEDS. The present findings suggest that existing quantitative research into referral rates or the effectiveness of therapies for ethnic minorities could be complemented by research into therapists' views and experiences.

The present study adds nuance to the evidence base by generating a series of awareness and subtle recommendations to address unmet need (section 4.6). Therapy with ethnic minority FDEDs may be impacted by differences in presentation which question the constraints of therapy models. This might be supported by the use of cultural genograms and scripts. Therapy may also be influenced by therapists who report feelings of restriction from service management in their endeavours to address the diverse needs. As such hierarchy in teams should be addressed by diversity in decision making. Additionally, therapists may fear to behave in culturally insensitive ways. Such fears may involve worrying about adapting models too much and being seen by services as doing the wrong thing. Fears may be addressed by providing regular reflective practice on culture and co-produced training for therapists. These issues could beneficially be considered in future research, by services and NHS guidelines. Addressing therapists' needs and helping them to feel supported might improve the therapeutic experience for ethnic minority FDEDs. This may free the creative space and enable comfort to address culture in therapy.

4.8 Limitations

4.8.1 Sample Diversity

There was a conscious decision to ensure the sample was representative of the ethnic make-up of people in London. In the general population, it is estimated that those of Black and Asian ethnicity constitute 31.8% of London's population (Race Disparity Unit, 2018). Ethnic minority participants appeared to be proportionally represented in this study, and they constituted 33% (4 out of 12) of the sample. Proportional

representation to the ethnic make-up of people in London was chosen over the ethnic makeup in London SEDs, to ensure a range of perspectives. Indeed anecdotally from personal observation having worked in two London SEDs the number of ethnic minority therapists working in this area is lower than the ethnic constitution in London.

From one perspective, most notably a quantitative approach, the mixed ethnicity of the participant group might be viewed negatively since it is not homogenous and reduces generalisability. From a qualitative perspective and a critical realist stance, this diversity gives rise to rich data. Ethnicity has a different meaning to every individual, making it a nuanced construct (Duncan & Trejo, 2017). This complexity might be viewed positively, and an attempt has been made to capture the complexities in the analysis. This includes how ethnic minority therapists might have different perspectives on therapy with ethnic minority FDEDs due to lived experience of culture and or shared ethnic identity with the people they work with.

4.8.2 Selection Bias

Attention was paid to ensure representation of a broad range of perspectives from the participant group. However, it is noted that specific participants, such as Avery are referenced more frequently than participants such as Saskia. This could be due to the articulation of concepts in a concise manner that exemplified the spirit or theme. Articulative answers may have been related to the level of experience or number of years working in SEDs. However demonstrating efforts to present a diverse range of experiences, quotes from across the participant group were included across the different themes.

There is also the possibility of selection bias through self-selection, whereby therapists who were more interested in the topic of culture in EDs, were more likely to take part. This may have led to rich data, but also to a more limited perspective. This is because therapists who are less interested or inclined to acknowledge cultural differences are unlikely to feature in the present study's analysis.

4.9 Reflexivity Revisited

I have been aware of the different identities I hold and the obligations these entail to maintain in-group identity and approval. Firstly, I am a researcher who aims to be faithful to therapists' reports of their experiences. Secondly, I am a soon-to-be qualified clinical psychologist who wants to work closely with other therapists without fear of having offended by way of this thesis. Thirdly, I am an individual from an ethnic minority who feels a duty to improve the experience of all SUs, including ethnic minorities, seen by SEDS. In the following, I balance these identities and reflect on the findings of the study in light of my personal experience.

4.9.1 Identity As A Researcher

As a researcher, it is necessary to be faithful in reporting participants views. However, during the interpretation of the data, I am also required to present possible latent meanings. I was aware of approaching the topic of ethnicity in EDs and the possibility of finding the results challenging to the status quo. This was perhaps amplified given my ethnic minority status and the dominance of Whiteness within the field of EDs. Much of ED practices in therapy and SEDs go unchallenged when applied to ethnic minorities, and this field is insulated in many ways. I was aware of how my fears of challenging might cause me to privilege findings which were more palatable. An example of this occurred when some participants cast blame to the parents for not seeking help due to shame or explained it was due to the parents' education or lack of awareness. From personal experience of having worked in SEDS, I am aware that such assumptions have been said by therapists; however, in such settings, I may have been reticent to challenge. Through reflexive thinking, I bought forward what I felt to be essential meanings in the data.

4.9.2 Identity As A Therapist

Having worked in SEDS, the topic of culture and ethnicity was rarely discussed in as much depth as might have been helpful. I often wondered whether therapists were considering these issues privately rather than more publicly in team meetings. The interviews made me aware that much of what is thought may be unsaid due to willingness to conform, or a desire to adhere to perceived management guidelines. I

was comforted by participants' awareness, enthusiasm and their ideas for research and the cause.

I was also aware that my previous work in SEDs might have caused me to empathise or align with particular views of the participants during the interviews. Attempts were made to ensure that I did not preferably encourage responses that endorsed my viewpoints. Before the interviews, I considered what my viewpoint was in some detail to be more aware of my own biases (section 2.7). During the analysis and write-up, I tried to maintain a focus on what my participants were saying and use the semi-structured nature of the interviews to allow participants to set the agenda. I sought to resist automatic alignment with the participants views. I tried to step out of my therapist identity and think about what might be driving their responses. I considered the possibility of hidden emotions and the broader factors which could have been involved, such as the societal, SEDS and NHS contexts behind their responses.

4.9.3 Identity As An Ethnic Minority

Participants from ethnic minority backgrounds were more likely to draw on their own experiences of being a minority within the UK and use this to assist their clinical work. I felt more comfortable probing and asking further questions in this context. These participants had lots to say, and it was evident that they had considered the topic before. During the interviews, I became aware of this, which prompted me to probe and encourage more in-depth answers from the White participants, in an effort to promote balance. Ethnic minority participants referred to how their ethnic minority status had contributed to their interest in this area. They had used their lived experience of being an ethnic identity to inform their understanding of ethnic minority FDEDs.

This led me to be reflexive and acknowledge that I often used my experiences of being an ethnic minority to help me understand the challenges involved for ethnic minroities and how this had fuelled the present research questions. During the interview process and analysis of the data, I was mindful of my potential to align with ethnic minority participants due to our shared identity of being an ethnic minority

therapist working in the field of EDs. I was aware of how this may have influenced my reactions during the interviews and also influenced responses. Furthermore, during the analytic process, I was mindful to draw on all participants' responses without preference for any particular ethnicity. This reflection led me to review some interpretations of the data to ensure that it did not favour one perspective of the issue.

4.10 Conclusion

This research set out to explore ethnic minority FDEDs through the perspective of therapists in terms of what working with this group means to the therapists themselves, their experience and their meaning-making. The research also explored how therapists perceive and work with cultural concepts. Due to my own identities of being an ethnic minority and a therapist who has worked in SEDs I took time to consider my viewpoint and biases, leading the research by focusing on the participants perspective and allowing them to set the agenda. Overall the research revealed therapists needs for support in their work and their perceptions of ethnic minority FDEDs. The participants had notions of shame as a barrier to FDEDs accessing help at SEDS. There were differing perspectives of how shame worked, and this, therefore, had different influences on their therapeutic work such as not challenging shame or assuming EDs in certain cultures are taboo and linking this to a negative interpretation of parents. There was also the concept that ethnic minority FDEDs might present differently with emotional and interpersonal factors more likely to be fuelling the ED, with perhaps a pejorative assumption that this was due to family dynamics. This appeared to conflict with the notion of acculturation and the western body ideal fuelling the ED. Curiosity was used to navigate cultural issues. However, participants personal interpretation determined whether behaviours were approached as a valid cultural factor or whether it was thought to be a feature of the ED that should be challenged and addressed in therapy. Participants also perceived a feeling of being restricted by the NICE guidelines and impositions by service management - having a limited time to reflect on culture, and the worry about being offensive or doing something wrong.

The findings have implications for therapists and services going forward. The recommendations propose encouraging new ways of thinking about the problem and questioning concepts that are perhaps taken for granted. Services and guidelines should support therapists to encourage a curious stance, in the knowledge that this will encourage their creativity and comfort in providing culturally appropriate therapy. This could include regular reflective practice on cultural issues where the ethos of these working environments could move to provide containment and a non-judgemental stance where questions can be flexibly discussed. The issue of

hierarchy (and how this could reduce the feeling of freedom to be creative to address individual differences) could be addressed by encouraging collaborative decision making in teams by ensuring diversity in clinical decision making in terms of job role, race and gender, perhaps by rotating who chairs and leads the meeting agenda. To break down the perceived barrier of shame and increase understanding on both parts, the use of cultural genograms and cultural scripts could be encouraged to understand the ED in context. Finally, to improve access and timely referral to SEDs for ethnic minority FDEDs, referral guides could be developed to inform therapists, GPs and teachers of the warning signs of EDs that may not be commonly acknowledged by diagnostic criteria.

This research revealed therapists enthusiasm for working with ethnic minorities in SEDs, albeit with aforementioned perceived barriers from services themselves and the perception of shame. Subtle steps can be taken to encourage new and creative ways of addressing the issues highlighted. The other half of the therapeutic alliance is therapists, and their role and input should not be understated when aiming for positive outcomes for ethnic minority FDEDs. Perhaps, the final word should go to one of the participants – Beth - who, rightly, observed:

"Not one model fits all and it's not a cookie-cutter model and you have to treat everyone as an individual." (Beth, Line 103-104)

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6 APPENDICES

Appendix 1: Summary table of papers in scoping review

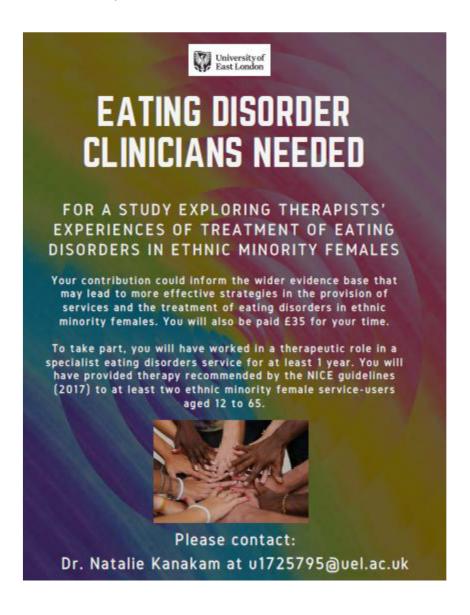
Paper, N=13	Methodology and findings	
(Mumford et al., 1991)	-Participants: representative sample of 204 South Asian	
	and 255 White Caucasian schoolgirls	
	-BN prevalence: South Asian 3.4% and White 0.6% with	
	the difference being significant (p<0.05)	
	-Questionnaire study	
	-Factor analysis of the EAT-26 and BSQ revealed cross	
	cultural equivalence in both groups	
	-High EAT and BSQ scores associated with a more	
	traditional cultural orientation	
(Bryant-Waugh & Lask,	-Participants: Four South Asian children diagnosed with	
1991)	EDs	
	-Case studies	
	-Rates of ethnic minorities FDEDs has increased	
	-Socio-cultural conflict between Asian and Western	
	culture as contributor to development of ED	
(Soomro et al., 1995)	Participants: 36 ethnic minority SUs diagnosed with AN	
	and 944 White SUs, over 34 year long database	
	-Clinical background similar between groups	
	-Ethnic minorities less likely to acknowledge sensitivity to	
	'fatness' (p=0.003).	
	- Numbers of EDs have not changed over time	
	- Ethnic minorities have same access to assessment and	
	treatment as White SUs	
(Lacey & Dolan, 1988)	-Participants: 5 Black and South Asian FDBN	
	-Case study	
	- Black and South Asian FDBN present with similar ED	
	features to White SUs	

	- Black and South Asian FDBN present with significant
	trauma and sexual abuse and response to treatment was
	poor
	- Referral ratio (ethnic minority 1: White 10)
(Ratan et al., 1998)	Participants: SUs presenting to Leicester SEDS. 21
	South Asians diagnosed with EDs over 10 years
	- South Asian people diagnosed with EDs present with
	similar ED features to White SUs
	-Referral rate for ethnic minorities was 25% of that for
	White people
	-Low referral rates for South Asians might be due to low
	prevalence or high clinical threshold for secondary care
(Tareen et al., 2005)	-Participants: N=14 South Asians with weight loss or
	diagnosis of AN compared to matched White peers
	-Case note study
	-South Asians more likely to present with loss of appetite
	(p = .01) and less frequently with fat phobia (p = .032)
	and weight preoccupation (p = .001).
	-South Asians also had significantly more satisfactory
	relationships with their family and peers (p=0.03)
	- South Asians may be more likely to present with the
	non-fat phobic form of AN
(Waller et al., 2009)	Participants: Catchment area cohort of 648 SUs
	assessed and treated at SEDS in South London
	- Ethnic minorities less likely to be referred to SEDS than
	White SUs
	- White SUs were more likely to have no diagnosable ED
	at assessment than ethnic minority SUs
	- Ethnic minorities were more likely to be diagnosed with
	BN than White SUs
	- Treatments offered did not differ between groups
(Abbas et al., 2010)	Participants: South Asians presenting to Leicester SEDS
	from 1991-2005. N=26 BN and n=43 EDNOS.

	-Comparisons made between South Asians and other
	ethnic groups
	-Asians underrepresented. Only 4.5% of SUs were Asian
	compared to making up 13.8% of local population
	-ED features were similar between groups, but South
	Asians were younger
(Chowbey et al., 2012)	Participants: Relatives of SU diagnosed with ED (n=3),
	key informants (n=15), group discussions with a
	representative sample of young ethnic minorities (n=24)
	-Data of young people, carers and key informants
	integrated for analysis
	Findings: Several factors impact access to treatment in
	ethnic minorities: poor past experiences with services,
	low public awareness, religious norms and cultural
	norms around food and body image can reduce early
	recognition of the ED. SEDS may also be slow to
	recognize EDs in ethnic minorities and lack confidence
	in how to approach their needs
(Solmi et al., 2014)	Participants: N=1698 people in the South East London
	Community Health Study, n=145 followed up with
	diagnostic interview
	-White (n=4, 66.7%) and Black females (n=2, 33.3%)
	were most likely to be diagnosed bulimia nervosa or BED
	(n=9, 92.4% and n=2, 7.6% respectively)
	-Purging disorder was most common in White (n=2, 50%)
	and Asian (n=1, 25%) or Other ethnic groups (50%).
(Wales et al., 2017)	-Participants: One ED professionals focus group (n=16),
	6 focus groups of South Asians from the local community
	in Leicester (n= 28)
	-Data of ethnic minority FDEDs and professionals
	integrated for analysis
	-Findings: possible factors which delay accessing SEDS
	include, lack of knowledge about seriousness of ED,

	family dynamics, role of food in culture, valued body		
	shape ideals, stigma associated with mental health and		
	concerns about confidentiality		
(Channa et al., 2019)	-Participants: 1 British Indian FDBN		
	-Interpretative phenomenological analysis		
	-Exposure to Western ideal of thinness contributes to ED		
	development		
	-Family thinness ideals contribute to ideal embodied self		
	-Body image and food has multiple meanings and are		
	rooted culture		
	-Mental health is a taboo is South Asian culture		
	associated with shame, anxiety and stigma		

Appendix 2: Recruitment poster and flier





Participant Information Sheet

Therapists Reflective Experiences of Eating Disorders in Ethnic Minority Females

Natalie Kanakam (Trainee Clinical Psychologist);

Email: u1725795@uel.ac.uk; **Tel**:

Address: School of Psychology, University of East London, Water Lane, London

E15 4LZ

I would like to invite you to participate in a research study. The study is part of my Doctorate in Clinical Psychology at the University of East London (UEL). Before you decide to participate, it is important that you understand why this research is being carried out and what your participation would involve.

What are the study aims?

The primary aim of this research is to improve the identification and treatment of Eating Disorders for ethnic minority females in the UK. Research in this area within the UK is still in its infancy, in comparison to the US. The present study aims to add to the UK research base by exploring therapists' experiences of working with ethnic minority females in specialist ED services.

Who can take part?

Therapists who have been working in a therapeutic role including: clinical/ counselling psychologist, family/systemic therapist, cognitive therapist or psychiatrist. You will need to have at least one year's experience of working in a specialist ED service. Participants will have provided NICE (2017) guidance recommended therapy interventions to at least two ethnic minority female service users aged between 12 and 65. Participants must be able to communicate in English and can be any age, ethnicity and gender.

What will happen if I agree to take part?

You will be invited to take part in an interview, which will explore your experiences of working with ethnic minority females. The interview will take place with the researcher either in person in a private room at UEL or local library or via Skype/telephone depending on your preference. In order to be as accurate as possible, I will ask your permission to audio record the interview, which will be anonymised (meaning you will not be named or otherwise identifiable). Please note, you will need to provide your consent before you will be able to proceed with the interview. This will be done either in writing in person, by post, email or verbally on the phone. In total, the interview will take no more than 90 minutes.

Will I be reimbursed for my time?

As a thank you for your time, you will be paid £35.

What else should I be aware of before making my decision?

The interview is not designed to cause discomfort or distress. The study requires reflection on clinical work which is considered a standard practice for therapists. After being provided with the information sheet, you will be given 48 hours or more to consider taking part. You will have opportunity to have your questions answered about the potential issues/risks of taking part. You are also allowed to withdraw from the study at any time and withdraw your data within a three-week window from the time you participate in the study.

You will be provided with the contact details of the chief researcher and my supervisor. As per ethical guidelines (BPS, 2014), time will be allocated at the end of the interview for a debrief in which you will be given an opportunity to reflect with the researcher on how you have found the research experience and raise any concerns, as well as to revisit consent and available support.

What are the benefits of taking part?

There is limited research in the field of ethnic minorities with EDs in the UK. Your contribution of sharing your experiences may inform strategies to improve treatment and access to services for ethnic minorities with EDs. Therapists could be viewed as key informants, who are able to offer the breadth of their experiences of working with ethnic minority females, in the context of their clinical knowledge of therapy and ED symptoms.

How will my confidentiality be protected?

All information about you will be treated confidentially and in accordance with the Data Protection Act 2018. Any personal contact details and signed consent forms with your information will be stored separately to interview material. Your responses to the interview will be anonymised and no identifying information will be shared with anyone outside the research team. Any audio-recorded information will be transferred to a password-protected computer file on a secure network and deleted from the recording device. Each participant will be given a pseudonym and any names of people and/or places mentioned will be changed during transcription. All information will be saved on a password-protected computer file on a secure network that only the researcher will have access to.

How will my data be used?

Anonymised extracts from the interview might be used in my doctoral thesis and any publications in journal articles but it will not be possible to identify you from these. We may use quotes within the analysis of the research and within the final report, but again these will be anonymised and you will not be identifiable.

How long will my data be kept for?

All names and/or contact details will be destroyed after data collection. Any remaining data will be destroyed within 3 years.

Who can I contact following the study if I have any questions?

Natalie Kanakam (Trainee Clinical Psychologist);

Email: u1725795@uel.ac.uk; **Tel**:

Address: School of Psychology, University of East London, Water Lane, London E15

4LZ

Research Supervisor: Dr. Trishna Patel (Email: <u>t.patel@uel.ac.uk;</u> Tel: 020 8223 6392)

If you have any questions or concerns about how the research has been conducted please contact the research supervisor: Dr Trishna Patel

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ. Email: tlomas@uel.ac.uk

Thank you for taking the time to read this information sheet



Participant Consent Form

Therapists Reflective Experiences of Eating Disorders in Ethnic Minority Females

Thank you for considering taking part in this research. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to take part.

Natalie Kanakam (Trainee Clinical Psychologist);

Email: <u>u1725795@uel.ac.uk</u>; **Tel**:

Address: School of Psychology, University of East London, Wate Lane, London

E15 4LZ

Please tick the boxes below to confirm:

Signed	Date
I would like to receive £35 for my participation in this study.	
I understand that I can decide at any point, without giving any reason, to stop participation and to have all my data withdrawn within a three-week window from the time of participating in the study).	
I consent to being audio recorded during the interview. Audio recordings will be transcribed by the researcher for use in the research analysis and within the final report and publication, within which I am assured my confidentiality and anonymity will be maintained and I will not be identified.	
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 Data Protection Act 2018.	
I understand the nature and purpose of the above-named study. I have been given an information sheet describing the research, and have had the opportunity to ask the researcher questions, to which I feel I have received satisfactory answers.	



Debrief Sheet

Therapists Reflective Experiences of Eating Disorders in Ethnic Minority Females

Natalie Kanakam (Trainee Clinical Psychologist);

Email: <u>u1725795@uel.ac.uk</u>; **Tel**:

Address: School of Psychology, University of East London, Water Lane, London

E15 4LZ

I would like to thank you for participating in this interview.

In 2014, the Government announced an additional £30m funding a year to support the development of dedicated community ED (ED) services across England. As such new guidelines were provided in 2015 to ensure increased recognition and treatment of EDs (NHS England, 2015). Despite this, the recognition and treatment of EDs for ethnic minorities requires further attention. Overall, this area of research is in its infancy.

As such ethnic minorities may experience difficulties in access to services and the treatment they receive. Firstly, it has been proposed that in the UK the low number of ethnic minorities presenting to specialist ED services (SEDs) is due to the lack of identification at primary care level (Waller et al., 2009). This may occur due to cultural biases in the recognition of EDs in ethnic minorities. At present the diagnostic system overlooks cultural phenomenological diversity since it is based largely on Western populations (Becker, 2007).

Secondly, the low treatment rates can also be accounted for by difficulties in help-seeking. There may be significant stigma associated with mental health problems and it may be felt that these difficulties are best helped with family support as opposed to involving external professionals (Wales et al., 2017).

Lastly, the most widely recommended treatment models for EDs do not specifically outline the inclusion of these cultural narratives into formulation and treatment. Therefore whether cultural nuances are incorporated into treatment is dependent on the therapist and the patient. Greater recognition of the diversity in symptoms might improve culturally competent care of EDs (Franko et al., 2007). Relevant cultural thinking and adaptations that have been reported by US service users include: the cultural influence on food choices, the meaning of food, acculturation to the dominant culture, support from family and their understanding and acceptability of ED treatment (Shea, Cachelin, Gutierrez, Wang, & Phimphasone, 2016).

The present study aims to explore the aforementioned issues:

- 1. What are therapists perspectives on how ethnic minority females diagnosed with EDs access Specialist ED Services?
- 2. What are therapists' experiences of working with ethnic minority females diagnosed with EDs in Specialist ED Services?

The present study will achieve this by exploring therapists' experiences of working with ethnic minority females in SEDs. Therapists may be seen as key informants who will be able to offer the breadth of their experiences working with ethnic minority females, in the context of their clinical knowledge of therapy and ED symptoms. By taking part in this study, you will be contributing to the wider evidence base that may lead to more effective strategies in the provision of services and treatment of EDs for ethnic minority women.

Once again, I would like to reassure you that all information about you will be treated confidentially. In addition, you can ask to have your information withdrawn without explanation within 3 weeks of participating. If you would like to find out more information about withdrawing from the study please feel free to contact the researcher whose contact details can be found below.

Who can I contact following the study if I have any questions?

Natalie Kanakam (Trainee Clinical Psychologist);

Email: <u>u1725795@uel.ac.uk</u>; **Tel**:

Address: School of Psychology, University of East London, Water Lane, London E15

4LZ

Research Supervisor: Dr. Trishna Patel (Email: <u>t.patel@uel.ac.uk;</u> Tel: 020 8223 6392)

If you have any questions or concerns about how the research has been conducted please contact the research supervisor: Dr Trishna Patel

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Tim Lomas, School of Psychology, University of East London, Water Lane, London E15 4LZ.

Email: t.lomas@uel.ac.uk

Thank you for taking the time to read this debrief sheet

Appendix 6: Participant questionnaire

Questionnaire What is your age? What is your ethnic origin? What is your gender? What is or was your job title when you worked with EDs? How long have you been qualified? How long have you worked with people who have EDs? How many ethnic minority clients have you provided interventions for? What type of therapeutic interventions have you provided for ethnic minority females with EDs? What ethnic minority types have you worked with? What are your qualifications? What are your training needs? Have you ever been provided with training on diversity for working across ethnic minority groups? If so where?

How confident do you feel working with ethnic minority females who have EDs on a scale of 1 to 10 with 1 representing not confident at all and 10 representing very confident?
18910
Please explain your answer:



Interview Schedule

Introduction by interviewer (to be communicated to participant): I'm going to ask you some questions about your experiences of working with ethnic minority females with ED diagnoses. I'm going to use 'ethnic minority' as a broad term to refer to those who are a non-White minority ethnic group within the UK. These include South and East Asian, Asian British, Black, African, Caribbean, Black British, Mixed or Multiple ethnic groups, Arab or other non-White minority ethnic groups. There are no right or wrong answers and everything you say will be anonymous. You can stop the interview at any time or take a break, and you don't have to answer any question if you don't want to.

Before we begin, do you have any questions for me?

Please could I check that I have your consent to record this interview?

Question 1:	To begin with, could you please give me some background on your current or previous role?		
Possible prompts:	 What's your professional background? How long have you worked with people who have EDs? Have you worked in more than one ED service? 		
Question 2:	How much experience have you had working with ethnic minorities who have EDs?		
Possible prompts:	 In your experience, what proportion of the people seen in your service are ethnic minority female? (encourage a guess) Is this what you would expect? Why/Why not? How much of your typical workload would involve offering therapeutic interventions to women of ethnic minority backgrounds? What ethnic minority groups have you worked with? 		
Question 3:	What is your understanding or experience of how women from ethnic minority groups access specialist ED services?		
Possible prompts:	 What factors do you feel influence how females from ethnic minorities are referred to specialist ED service? 		

	 What have you noticed about patient factors, Therapist factors, Systemic level (Services criteria, NICE guidelines) factors Have you noticed any differences in referral patterns or access issues for females in different ethnic minority groups? What have you noticed?
Question 4:	What are your thoughts on using NICE-recommended treatments when working with females from ethnic minorities?
Possible prompts:	 In your experience, are there any particular challenges? Are there any benefits? Have you ever deviated away from the prescribed model? What guided your decision to deviate? Can you give an example? Do other professionals share the service views? What are the ED service expectations about what treatments to offer? Is there any difference in your personal and professional views on this?
Question 5:	Say an ethnic minority (let them name a minority) woman had been referred to you and you were going to meet her for the first time – what sorts of things would you have in mind to prepare for the session and make sure it went well?
Possible prompts:	 How do you feel when trying to take culture into account? Are there any gaps in your knowledge? What are they? How did you overcome the gaps in your knowledge? What are your thoughts on how staff could overcome these more broadly
Question 6:	Have you ever adapted an ED therapeutic intervention to meet the needs of ethnic minority females? Can you give me an example? What sorts of adaptations have you made to your therapeutic practice?
Possible prompts:	 (if not brought up by therapist explore around: Therapeutic emphases Cultural adaptations to mainstream therapy Working with family dynamics Any other factors that influenced their adaptations?
Question 7:	Have you seen any differences in how EDs are understood by ethnic minority females that you have worked with? If yes, in what way?

Possible prompts: Question 8:	 What do you feel might have influenced how these clients thought of their EDs? Are there any particular cultural values that stand out to you as being influential? What do we need to be thinking about in terms of ethnic minority women's families? What impact does being minority ethnic have on strengths and risk factors? Suppose you could wave a magic wand and things were improved
	for ethnic minority females with EDs. What would be some of the things you would notice that would tell you things had suddenly gotten better
Possible prompts:	 Patients? Families? Communities? Therapists? Systemic level (Services, NICE guidelines)?
Question 9:	We are coming to the end of the interview. Just before we finish I'd like to ask, if you were in my chair what do you think would be the most important question I could be asking?

I would like to check that you still consent to your anonymised data being for this study. I would also like to remind you that you have the right to have all you data withdrawn until your data is anonymised

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational
Psychology

REVIEWER: Kenneth Gannon

SUPERVISOR: Trishna Patel, Matthew Jones Chesters

STUDENT: Natalie Kanakam

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: Exploring Therapists Reflective Experiences Of Working With British Ethnic Minority Females With Eating disorders.

DECISION OPTIONS:

- 1. APPROVED: Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
- 2. APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is <u>not</u> required but the student must confirm with their supervisor that all minor amendments have been made <u>before</u> the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
- 3. NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

(Please indicate the decision according to one of the 3 options above)

APPROVED

Minor amendments required (for reviewer):
Major amendments required (for reviewer):
Confirmation of making the above minor amendments (for students):
I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.
Student's name (Typed name to act as signature): Student number:
Date:
(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)
ASSESSMENT OF RISK TO RESEACHER (for reviewer)
Has an adequate risk assessment been offered in the application form?
YES / NO
Please request resubmission with an adequate risk assessment
If the proposed research could expose the <u>researcher</u> to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:
HIGH
Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.
MEDIUM (Please approve but with appropriate recommendations) X LOW
A LOW
Reviewer comments in relation to researcher risk (if any).

Reviewer (Typed name to act as signature): Dr Kenneth Gannon

Date: 07/08/2019

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

Appendix 9: Example of annotated transcript

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Interviewer:
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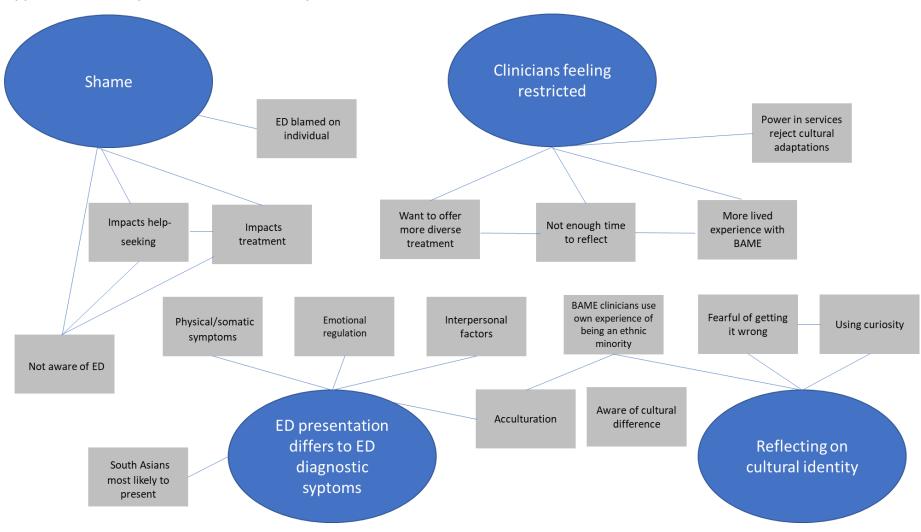
Appendix 10: Intermediate codes

1	A risk factor for ethnic minority service-users is migration
2	Ethnic minority service-users don't seek help due to shame and stigma
3	Treatments offered in service are strictly aligned with NICE guidelines
4	Ethnic identity depends on persons individual experience
5	Clinicians would like to talk more about culture in supervision
6	Ethnic minority patients are more chronic
7	Need to spend more time with ethnic minority exploring the meaning of EDs
	Awareness of eating disorders should be raised to increase referrals for ethnic
8	minority service-users
9	The desire to adapt treatment conflicts with management in service
10	NHS austerity means there is reduced time to reflect on culture
	Ethnic minority service-users more likely cite that they have no appetite as
11	reason for not eating
12	Ethnic minority service-users seek help from family first
	Clinicians cite they are more comfortable with cultures adaptations for service-
13	users they have had more experience with
	Would like to visit service-users in their home to experience eating and
14	customs
15	Treatments are developed on White populations
16	Eating disorder is kept secret from family
17	I don't approach ethnic minority and White patients differently
18	Family places responsibility on expert clinicians to solve the eating disorder
19	Younger ethnic minority service-users are more likely to have less shame
20	NHS austerity means there is reduced time to make adaptations
21	Use curiosity and questions to guide intervention
22	Unaware of eating disorders
23	Clinicians are fearful of getting it wrong when proposing cultural adaptations
24	Clinicians shouldn't judge family by western standards
25	
	NICE guidance treatment is not always applicable to the presenting problem
26	NICE guidance treatment is not always applicable to the presenting problem Diversity training doesn't not cover gaps in knowledge

28	Overcome gaps by asking patient
29	Isolation restricts exposure needed for eating disorder recognition
30	Rejection of ethnic food may represent desire to acculturate
31	Ethnic minority service-users are less likely to self-refer
32	Ethnic minorities deny their symptoms due to shame
33	ED is more about emotion regulation
	Ethnic minority service-users may acculturate as a form of individuation from
34	their family
35	Mental health is associated with shame in ethnic minority
	Clinicians are aware of being White and the cultural difference with ethnic
36	minority service-users
37	Cultural adaptations to address shame
38	Ethnic minority service-users don't' see ED as a serious problem
39	Less likely to present with weight and shape concerns
	With ethnic minority service-users, family therapy model should be used to
40	include family
41	Eating disorders formulated differently for ethnic minority females
42	More ethnic minority service-user involvement
	NICE guideline treatment is good starting point for ethnic minority service-
43	users
	Ethnic minority service-users do not fit criteria for specially commissioned
44	service
	Clinicians are worried about being seen to go against management guidelines
45	when incorporating cultural adaptations
46	Mental health is understood differently in ethnic minority populations
47	Never make assumptions about patients' culture
48	Within each culture there are differences
49	Family do not understand the eating disorder
50	Adaptations are unique to each patients intervention
	Clinicians would like more training in NICE culturally sensitive treatment
51	models
52	Eating disorder is blamed on individual
53	Clinicians want to be able to offer more diverse treatments

55	Ethnic minority mums are more likely to attend therapy sessions with child
	A risk factor for ethnic minority service-users is balancing the need to comply
56	to cultural norms at home whilst assimilating to British culture
57	Ethnic minority patients have later referral
	Treatment engagement impacted by ethnic minority service-users wanting to
58	keep treatment hidden from family
59	I have gaps in my knowledge about culture
	Ethnic minority therapists draw on their own experiences of being an ethnic
60	minority when working with ethnic minority service-users
61	Ethnic minority patients more likely to present with somatic symptoms
62	Acculturated ethnic minority patients are more likely to seek help

Appendix 11: First provisional thematic map



Appendix 12: Second provisional thematic map Clinicians feeling Shame restricted Want to offer More lived Impacts help-Not enough time Impacts more diverse experience with to reflect seeking treatment treatment BAME BAME clinicians use own experience of Fearful of getting Physical/somatic Emotional Interpersonal Using curiosity being an ethnic it wrong regulation factors symptoms minority Not aware of ED Acculturation ED presentation differs to ED Reflecting on cultural identity diagnostic symptoms

Appendix 13: Reflective journal extracts

Example excerpt of entry following interview:

I have just finished my eight interview. The interview made me feel exhausted, as is common afterwards. The levels of concentration needed to follow what is being said and question deeper when needed. Also I feel worry about saying the wrong thing, that may offend the interviewee, if I question too much or if I lead their answer. I'm so conscious of trying to ensure she doesn't feel like she is being tested or interrogated. Although I wonder where this feeling comes from. Is it that I find it difficult to approach this topic, or it is their discomfort around the topic. Or perhaps due to the role of being the interviewer and the position of power this entails.

In this interview I was comforted to hear her enthusiasm for the topic. It came across that this is something she had thought about before. I am starting to notice a pattern of responses across the interviews. A lot of which I have felt similar to when working in eating disorder services in London. It's difficult to know how much it is their views or mine. I own my position and try to be aware of that when absorbing the interviewees responses. I am trying hard to distinguish and not selectively hear their responses.

I'm comforted that this interviewee had noticed and even pondered these topics. Maybe it was something that she had in the back of her mind whilst working in her service. Although I personally rarely heard such open conversation about race and the inequalities when working in services. Hearing what these interviewees have to say, makes me realise that it is something they have reflected on, albeit not publicly. Maybe feeling too scared to speak out, against those who employ them. I had often wondered if anyone considers these issues. In comparison to another interview I felt that she had not reflected and there was little in her response. Although that seems to be in the minority.

Although this interviewee had ideas for what could be done or what she has done, overall, it felt general and specifics felt limited. There seemed to be a genuine interest

on her part, despite her not being an ethnic minority herself. There seems to be some references to more overt adaptations such as incorporating religious leaders. At times it feels as though more subtle differences are overlooked. Nevertheless I was surprised or maybe impressed that this interviewee went a bit further to even question, common cultural adaptations that are based on small sample sizes such as non-fat phobia. This made me question my own views on non-fat phobia.

Entry following preliminary stages of analysis:

Coding of the interview makes me feel overwhelmed. There seems to be so much to code. I feel the stress of wanting to make sure that I capture each participants story, without missing or overlooking due to my own perception of things. It's a painstakingly long process followed by going back over the transcript to ensure anything in the way of alternate or hidden meanings wasn't missed. At times I feel emotionally attached to some codes. I feel a sense of loss and worry. I'm aware that my own identities as an ethnic minority and as someone who has previously worked in SEDS contribute to this and influence how I code and analyse. It is a challenge to balance the subjective approach to interpreting the data and the objective approach to coding. Reflecting on this balance, is the reiterated awareness to be aware of how my own personal and professional experiences shape the interpretations and my duty to represent the participants voices fairly. I am also mindful of how my participants are aware of me being an ethnic minority and how this inevitably shaped how they respond, possibly encouraging responses and discouraging some. I am also aware of the outcome of this research in terms of the implications and recommendations and ensuring this is communicated in such a way that is ethical and fair for both participants and ethnic minority service users