Improving understanding and access to treatment for Eating Disorders among British South Asian females.

A thesis submitted to the University of Manchester for the degree of Doctor of Philosophy (PhD) in the faculty of Medical and Human Sciences

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THE UNIVERSITY OF MANCHESTER

ABSTRACT OF THESIS submitted by Bushra Nazir

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and entitled: Improving understanding and access to treatment for eating disorders among young British South Asian females: a qualitative study.

Month and Year of submission September 2015

Introduction: Eating disorders were previously regarded as a Western culture-bound syndrome affecting only young Western women. However they have been described in the UK and in across the world. Research has highlighted the prevalence of disordered eating among South Asian females. However little is known about the process of how this comes about, and little qualitative research has been conducted in this area. This research aimed to understand the issues relating to the development and maintenance of eating disorders among South Asian females and their help seeking behaviour, as well as the barriers to accessing treatment.

Methods: Three main studies were carried out: two systematic reviews, a review of prevalence (study 1), a qualitative review (study 2) and a qualitative study (study 3). For study 1, the review was planned and reported with reference to MOOSE guidelines (Stroup et al 2000) for systematic reviews of observational studies. For study 2, the quality of the studies was appraised in accordance with Critical Appraisal Skills Programme Criteria (CASP 2013), qualitative research check list. For both reviews, a systematic literature search was conducted across four data basis, Psychinfo, Medline, CINAL and EMBASE. All articles were screened against inclusion/exclusion criteria. The data extracted from the selected studies was tabulated in a way that demonstrated the methodological robustness and cultural quality of each study was also reported. For the qualitative study (study 3), semi-structured interviews were carried out with three groups of participants, ten South Asian females with eating disorders, seven parents and siblings and eighteen health care professionals.

Results: For study 1, thirteen studies were initially selected. Overall, these studies reported higher prevalence of Bulimia among Asian females in the UK compared to Caucasian females. Studies conducted in Pakistan and India reported a lower prevalence rate of diagnosable eating disorders than reported in Western countries. In study 2, three studies were selected. They identified important themes; cultural conflict and controlling families. In study 3, two overarching themes were identified with corresponding sub-themes; development and maintenance of eating disorders in the context of family and cultural conflict; barriers and facilitators to accessing treatment.

Conclusions: Reviewed prevalence study findings highlighted a need to consider the adaptation of measuring tools, as eating disorders may present differently in different cultures, and diagnostic criteria based on Western norms may not always be appropriate. There was a lack of qualitative studies and those available were of poor quality. The main aetiology and maintenance of Eating Disorders reported by South Asian females were focused on conflict with family and culture. Seeking treatment was difficult for these women due to stigma, shame, issues of confidentiality and lack of training and understanding in cultural competence among health care professionals.
Declaration

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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ED</td>
<td>Eating Disorders</td>
</tr>
<tr>
<td>AN</td>
<td>Anorexia Nervosa</td>
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<tr>
<td>BN</td>
<td>Bulimia Nervosa</td>
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<tr>
<td>BED</td>
<td>Binge Eating Disorder</td>
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<tr>
<td>EDNOS</td>
<td>Eating Disorder Not Otherwise Specified</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>NICE</td>
<td>National Institute of Clinical Excellence</td>
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<tr>
<td>DSM</td>
<td>Diagnostic Statistical Manual</td>
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<tr>
<td>ICD</td>
<td>International Classification Diseases</td>
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<td>BMI</td>
<td>Body Mass Index</td>
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<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
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<tr>
<td>IPT</td>
<td>Interpersonal Therapy</td>
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<td>EDE- Q</td>
<td>Eating Disorder Examination Questionnaire</td>
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This thesis is dedicated to all of you especially to my daughter Amarah.
Section 1

Introduction & Background to thesis
Chapter 1

Background to thesis
1.1 Rationale & background

Eating disorders are amongst highest causes of disability among young women, (Mathers, Vos, Stevenson & Begg, 2000). Anorexia nervosa has the highest mortality rate of all mental health problems (Arcelus, Mitchell, Wales & Nielson, 2011) ranging from 0.3% to as high as 20.0% (Nielson, 2001), because of the often irreversible health damage (Treasure et al, 2010; Van Hoeken et al 2003) and suicide risk (Harris & Barraclugh, 1996). Individuals often experience comorbidities including psychological and longer term physical complications; such as depression, anxiety, self-harm, substance misuse, cardio-vascular problems, fertility problems and osteoporosis, amongst numerous others (Fairburn & Brownell, 2001). Such comorbid long term physical and psychological problems have associated impacts on social functioning such as relationships and employment prospects (NICE 2004).

Eating disorders were historically regarded as a Western culture-bound syndrome affecting only young affluent Western women (Brunch, 1973; Prince, 1983). The predominance of culturally bound behaviours in the clinical presentation of eating disorders was assumed by early researchers to suggest a relationship to wider social critiques of the conditions of Western modernity. Increasingly Eating Disorders have been reported across a range of ethnic groups in the United Kingdom (UK) (Bhadrinath, 1990; Bryant-Waugh & Lask, 1991; Lee, 1991) and across the world, including Nigeria (Nwaefuna, 1981), Malaysia (Buhrich, 1981), Egypt (Nasser 1994) and Iran (Nobakht & Dezhkam 2000). However little is known of the incidence or prevalence in Asia (Treasure & Schmidt, 2002). Such studies have increased interest in the presentation of eating disorders in non-Western and non-white populations and have led to the suggestion that the study of eating disorders in diverse groups is essential to improving our understanding of how social cultural influences may be related to their development (Dolan, 1991; Smolak & Striegelmoore, 2001). Moreover eating disorders often go unrecognised in ethnic minorities or are only acknowledged after they have progressed to a more severe stage (DiNicole, 1990; King, 1993).

The principle aim of this research was to understand the issues relating to the development, maintenance of eating disorders and help seeking behaviour and
barriers to accessing treatment for eating disorders among South Asian females, also family and cultural issues that might contribute to those barriers and maintenance or that facilitate treatment seeking and recovery.

This thesis begins by systematically surveying the available literature, identifying the gaps in existing knowledge through conducting three main studies, two systematic reviews (studies 1&2) of quantitative and qualitative studies examining the prevalence of eating disorders among South Asian females and any qualitative research on Asian females and eating disorders; and also a qualitative study (study 3) which examines eating disorders and South Asian females, mainly focusing on Pakistani, Indian and Bangladeshi women, through semi-structured interviews. For each of these studies, their aims will be highlighted below.

1.2 Section 2: Chapter 2: Overview of literature - outlines the symptomatology, epidemiology and aetiology of eating disorders and provides background information and existing literature on eating disorders and South Asian females within the UK and the Asian-subcontinent focusing mainly on Pakistan, India and Bangladesh. It will explore literature on why South Asian females have inadequate access to mental health services.

Other reviews have been carried out, for example Cummins et al (2005) examined eating disorders within South Asians populations but only studies up until 2001 were included. A more recent review by Brown et al (2009) examined ethnicity, body dissatisfaction and eating disorders, but because it was published by American authors it mostly includes East Asian populations for example Chinese and Hispanic. Therefore, to systematically review both quantitative and qualitative studies was considered by the present author to be important as there has been a decade of studies since the previous reviews.
1.3 Section 3: Chapter 3: Overview Systematic reviews - presents the methods and findings for two systematic reviews:

Study 1: Is a systematic review of studies on the prevalence of eating disorders among South Asian females, particularly of Pakistani, Bengali and Indian ethnicity in UK and the subcontinent. This will aid our understanding of prevalence in this population, and possible associated factors.

Aim of the quantitative systematic review was to:

a) Review evidence of the prevalence of eating disorders among South Asian females in the UK and the Indian subcontinent
b) Consider the possible associated aetiological factors revealed by these studies
c) Review the methodologies employed within studies included in the review, and their main findings
d) Consider the quality of included studies.

Chapter 4: Study 2: A systematic review of qualitative studies of eating disorders among South Asian females in the UK and the Indian subcontinent.

There is a need to summarise any existing qualitative research on South Asian females and eating disorders in order to develop our understanding of treatment, needs and expectations; and aetiological and maintaining factors that they may perceive to contribute to the aetiology of their eating disorder. This review, aimed to include all relevant qualitative studies of eating disorders among South Asian females in the UK and the Indian subcontinent.

Aim of the qualitative review was to:

a) Summarise qualitative studies, on South Asian females with eating disorders focusing on specific factors that are thought to lead to the development and maintenance of eating disorders in the UK and the Indian subcontinent.
b) Review the methodology employed within studies included in the review
c) Consider the quality and ‘cultural’ quality of the studies.
1.4 Section 4: Overview of Qualitative Study 3: A qualitative study of the experiences and perception of eating disorders of South Asian females with eating disorders, family members and health care professionals.

Chapter 5: Methodology: presents Study 3, which expands on the previous reviews by conducting a qualitative study of the experiences and perception of eating disorders of South Asian females with eating disorders, their family members and health care professionals. This study used qualitative methods of research and thematic analysis, through one-to-one interviews with service users, family members and health care professionals, with the aim of increasing understanding of the psychosocial factors that South Asian females with eating disorders perceive to be important in the development and maintenance of their condition and the difficulties that they experience in accessing services. This study aimed to understand issues relating to help seeking and barriers to access to treatment for eating disorders among young British South Asian females, through qualitative methods of research and also to highlight family and cultural issues that might contribute to barriers and maintenance or that facilitate treatment seeking and recovery. The main aims of this study were to understand the issues relating to eating disorders and South Asian females through:

a. Exploring their perceptions in respect of their experience of health care and their views on the role of family in facilitating or as obstacles to receiving effective care.

b. Examining perceptions and understanding the family members around eating disorders and their experiences of living or caring for a family member suffering from an eating disorder.

c. Exploring perceptions of health professionals, including experiences of providers of services for eating disorders, about potential barriers and facilitators to accessing care for this population.

This study will add to our understanding of how cultural and ethnic background contribute to the development and maintenance of eating disorders among young British Asian females and give an insight into their coping strategies. It will also
highlight barriers and potential facilitators to treatment and give main findings and conclusions.

**Chapter 6: Study 3 – Results**

A detailed description of each main theme and sub-themes will be discussed with reference to direct quotes from the participants’ transcripts.

**Section 6: Chapter 7: Over all Discussion and Conclusions**

This section provides an overall discussion of the three studies, suggestions and ideas for future research and practical application of the findings. It will discuss the key findings of Chapter 5, in particular the two overarching themes: Family and cultural conflict, and possible barriers to accessing treatments.
Section 2
Chapter 2
Overview of the literature
2.1 Overview of literature

There is a concern among clinicians and researchers alike that anorexia nervosa, bulimia nervosa and eating disorders not otherwise specified (EDNOS) are becoming increasingly common (Hoek and van Hoeken, 2003; Palmer, 2000; van Hoeken et al, 2003). Traditionally, eating disorders were regarded as a Western, culture-bound syndrome and to affect only young, affluent Western women (Brunch, 1973; Prince, 1983). However, they have been increasingly described in studies across the world and other ethnic groups (Bhadrinath, 1990, Lee, 1991).

In the United States of America (USA), twenty million women suffer from a clinically significant eating disorder at some time in their life (Wade et al 2011) and more than 1.6 million people in the UK are affected by eating disorders (BEAT 2007). There are more deaths from eating disorders than from any other mental illness, and it is estimated that 10% of all sufferers die as a result of their condition (NICE 2013). The Health and Care Information Centre published new figures in February 2014 showing an 8% rise in the number of inpatient hospital admissions in the twelve months previous to October 2013. These only include those affected by eating disorders who were in inpatient NHS treatment.

In the general population, incidence rates reported vary greatly depending on the population studied, type of disorder assessed and methodology used (Pike, 2005; Micali, Hagberg, Peterson & Treasure, 2013). It has been estimated that as many as one woman in twenty have eating habits which give cause for concern (MIND, 2009), and most are aged between 14 and 25 years old but eating disorder can also affect people as young as six (Ballard, Handy, McGibben, Mohan & Silveira, 1993; National Eating Disorders Association, 2006), or as old as seventy (Orbach, 1992; Mangweth-Matzek, 2006). However, this is likely to be an underestimate of the true prevalence, since eating disorders are largely hidden, due to the difficulty in detection and in reluctance to report. The incidence rates often reflect cases that receive formal clinical recognition, rather than incidence rates for the general population (Smink, Van Hoeken & Hoek, 2012). These figures therefore leave out those who have not come forward, have not been diagnosed, are receiving private treatment, or are being treated as an outpatient or in the community (BEAT 2015). It
can be highlighted that South Asian females may be more likely to be among these groups, as they are less likely than other groups to access services (Nazroo, 1997).

It is recognised that eating disorders affect adolescents from all socio-economic backgrounds (Sing Lee 2000) and from different ethnic backgrounds; (Hill & Bhatti, 1995; Mumford & Whitehouse, Choudry, 1992; Mumford, Whitehouse & Platts, 1991). It has been highlighted that South Asian females may have a higher prevalence of clinical bulimia and unhealthy eating attitudes in childhood and adolescence (Ahmed et al., 1994) and in adulthood (Dolan et al., McCourt & Waller, 1996).

Although it is generally accepted that sociocultural factors are the key in eating disorder aetiology, knowledge on how best to study these influences in diverse groups remains limited. Even less is known about the degree of distress experienced by ethnically diverse populations in relation to eating disorder symptoms (Borowsky et al 2000). Therefore it is important to understand what causes it. Eating disorders characteristically involve a psychosocially complex aetiology, and there are multiple sociocultural, biological and individual vulnerability factors that may predispose an individual to eating pathology. Such complexity can make it difficult to prevent and very hard to treat (Treasure and Schmidt, 2003). The sections below will discuss these factors, in particular our present understanding of what eating disorders are and what maintains them within the general population and how they are becoming more prevalent in South Asian females. The later will also be discussed in more detail in chapter 2.

2.2 Historical background, classification and definition of Eating Disorders.

Eating Disorders
An eating disorder is a psychological condition characterised by a persistent, severe disturbance in a person’s eating attitudes and behaviour that result in insufficient or excessive dietary intake, which can cause serious physical and psychosocial impairments (American Psychiatric Association 2014). Eating disorders are typically
classified according to guidelines known as the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM) 4th Revision (DSM-IV; APA, 1994), or the International Classification of Diseases (ICD-10) (WHO, 1992). The DSM defines three types of Eating Disorders (ED): Anorexia Nervosa (AN), Bulimia Nervosa (BN) and Eating Disorder not Otherwise Specified (EDNOS); (see table 1). Anorexia nervosa is characterised by low body weight, a fear of becoming fat and body image distortion. In Bulimia, low weight is not necessarily present, but binging and purging as well as body image distortion are features. Eating disorders that do not meet the full criteria of either diagnosis are characterised as EDNOS.

There are two main classification systems; Diagnostic and Statistical Manual (DSM) most frequently used in the US but elsewhere too; the latest version is DSM-5 (DSM-5 APA, 2013), and The International Classification of Disease (ICD) which is used within the across much of the world and in the British NHS. The DSM-5 cities the main eating disorders as Anorexia Nervosa (AN), Bulimia Nervosa (BN) and Binge Eating Nervosa (BED), eliminating EDNOS (eating disorder not otherwise specified). The next version of ICD is due to be published in 2017 (ICD-11) and is likely to include Binge Eating Disorder in its own right (International Advisory Group 2011).

Prior to the new version of DSM, the breakdown was estimated that those with eating disorders: 10% were anorexic, 40% were bulimic and the rest fell into the EDNOS category which included BED (DSM-IV, American Psychiatric Association, 2000). The diagnostic categories for eating disorders have been specified and refined over the years in both the American (DSM) and the World Health Organization (ICD) systems of classification. However the increasing narrowing of diagnostic categories has led to a growing number of individuals who do not fit neatly into either an anorexia nervosa (AN) or bulimia nervosa (BN) diagnosis receiving the diagnosis “eating disorders not otherwise specified” (EDNOS). Some researchers have begun to study more broadly defined phenotypes including sub threshold cases and to focus on attitudinal and behavioural traits rather than full syndromes, (Schmidt, 2003).
Anorexia Nervosa

Anorexia Nervosa is a condition that was first reported by Charles Lasegue (1873) in France and William Gull (1874) in Britain (Bruch, 1977). They both recognised that the disorder was associated with severe emaciation and amenorrhoea, inexplicable in terms of known causes of wasting. They were both extremely cautious about the nature or origin of the mental disorder, whilst at the same time recognising that there was a ‘morbid mental state’ (Gull), and ‘perversity’ (Gull; Lasegue) or ‘hysterical anorexia’ (Lasegue) (Bruch 1977). Subsequently many other case reports of anorexia nervosa were published in the 19th century, for example Bruck’s 1978 work known as the Golden Cage: the Enigma of Anorexia Nervosa. Anorexia Nervosa is an eating disorder where preoccupation with weight and shape is characterized by significant voluntary reduction of food intake and dramatic weight loss (Palmer, 2000). This illness has a long history, dating back to biblical times (Silverman, 1995). Anorexia Nervosa is cross-culturally universal (Keel & Klump, 2003) in that its incidence and prevalence has been recorded in all at some point in time.

Although the medical facts of anorexia nervosa have been documented as early as 1870 (Bruch 1977), prior to 1983, almost no one outside of the medical community had heard of anorexia nervosa or bulimia (Bruch, 1977). The case study of Ellen West (1930-1933), provided Ellen’s perspective, describing her desperate obsession with food and thinness that eventually led to suicide. It was the death of the popular singer Karen Carpenter in 1983 that brought eating disorders to the attention of the general public (Schmidt 2010). Since the late 1980’s, many specialist eating disorder clinics have opened (Casper, 1983). During the 1990’s, the first reports of Princess Diana’s battle with bulimia appeared in Andrew Morton’s 1992 book Diana: Her True Story, and subsequent media interest might have focused attention on bulimic symptoms and improved public awareness of the disorder (Stice et al, 1994). Leila Pahlavi, the youngest daughter of the late Shah of Iran, died aged 31, suffering from years of Anorexia and Bulimia (Independent, 2001).
Bulimia Nervosa

Bulimia Nervosa emerged in the 1960s as a common characteristic of Anorexia (Russell 1979). Bulimia is characterised by binge eating, which means, consuming huge amounts of food, up to 60,000 calories at a time (American Psychiatric Association, 1994). To compensate for the huge food intake, individuals with bulimia often resort to vomiting and using laxatives (Pomeroy & Mitchell, 1991).

The symptoms of self-induced vomiting and laxative abuse, rarely mentioned before the 1930’s (Casper 1983) have become central features of the now separate syndrome, Bulimia Nervosa, as well as being symptoms of Anorexia Nervosa. Bulimia Nervosa was first formally described by Russell (1979), and since then the prevalence has risen (Collier & Tressure 2004). Bulimia was introduced in psychiatric classifications in 1980 (American Psychiatric Association, 1980).

Atypical eating disorders including binge eating disorder

Many people with an eating disorder do not meet the full criteria for a diagnosis of Anorexia or Bulimia Nervosa. ICD-10 therefore includes two further categories: Atypical Anorexia Nervosa and Atypical Bulimia Nervosa. DSM-IV instead includes a category of ‘Eating Disorder Not Otherwise Specified (EDNOS), which includes the condition of Binge Eating Disorder (BED). People with BED engage in frequent binge eating but do not show the compensatory behaviours that are characteristic of Bulimia Nervosa. (Please see table 1 for Diagnostic criteria for eating disorders based on ICD-10 and DSM-5).

By the 1980’s, eating disorders were commonly thought of as an extreme manifestation of societal obsessions with thinness, with common subclinical syndromes present in the population. In the 1990’s this causality shifted to gender dynamics, focusing on power and self-determination, rather than being related to the biology of female gender. Current sociocultural explanations include worldwide cultural dynamics, such as cultures in transition (“Westernising” societies) and confused gender identities. The biggest change in the perception of eating disorders came in the 1990’s, when converging evidence from twin and family studies showed that they have a genetic component (Collier & Treasure, 2004).
There is also increasing awareness that the underlying personality and behavioural traits have utility in classifying eating disordered individuals into diagnostic subgroups, particularly those with restricting-type AN whose personality has been uniformly described as anxious, harm-avoidant, low on novelty seeking, perfectionist, persistent, obsessive, compulsive and with diminished self-directedness (Klump et al, 2000). The personalities of individuals with a diagnosis of anorexia nervosa are commonly characterised by perfectionism, obsessionality, anxiety, and low self-esteem (Bulik et al, 1997).
Table 1: Diagnostic criteria based on ICD-10 and DSM-5 for anorexia nervosa, bulimia nervosa, EDNOS and AED.

<table>
<thead>
<tr>
<th></th>
<th>ICD-10 (World Health Organisation)</th>
<th>DSM-5 (American Psychiatric Association)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Produced by global health agency of UN Free and open resource for public health benefit For countries; and front-line service providers Global, multidisciplinary, multilingual development Approved by World Health Assembly</td>
<td>Produced by American Psychiatric Association Intellectual property of APA Primarily for psychiatrists and psychologists Dominated by US, Anglophone Perspective Approved by APA Board of Trustees and APA Assembly</td>
</tr>
</tbody>
</table>
| Anorexia Nervosa        | A. Weight loss, or in children a lack of weight gain, leading to a body weight of at least 15% below the normal or expected weight for age and height.  
B. The weight loss is self-induced by avoidance of “fatty foods”.  
C. A self-perception of being too fat, with an intrusive dread of fatness, which leads to self-imposed low weight threshold.  
D. A widespread endocrine disorder involving the hypothalamic-pituitary-gonadal axis, manifest in the female as amenorrhoea and in the male as loss of sexual interest and potency.  
E. Does not meet the criteria A and B of Bulimia Nervosa | Significantly low body weight in the context of age, sex, development trajectory and physical health;  
Fear of fatness even though the individual is underweight;  
An undue influence of body weight and shape on self-evaluation; Restricting type  
Binge-eating/purging type |
| Bulimia Nervosa         | A. Recurrent episodes of overeating (at least two times per week over a period of three months) in which large amounts of food are consumed in short period of time.  
B. Persistent preoccupation with eating and strong desire or a sense of compulsion to eat (craving).  
C. The patient attempts to counteract the fattening effects of food by one or more of the following:  
(1) self-induced vomiting;  
(2) self-induced purging;  
(3) alternating periods of starvation;  
(4) use of drugs such as appetite suppressants, thyroid preparations or diuretics.  
D. A self-perception of being too fat, with an intrusive dread of fatness (usually leading to underweight). | Eating in a short period of time an unusually large amount of food accompanied by a sense of loss of control over the quality of food eaten (binge eating episode);  
The binge is followed by inappropriate compensatory behaviours, defined by vomiting, inappropriate use of laxatives, diuretics, water pills, diet pills, fasting or exercising excessively.  
Binge–eating and compensatory behaviours occur at least once a week for a minimum of 3 months.  
An undue influence of body weight and shape on self-evaluation; This disturbance does not occur |
<table>
<thead>
<tr>
<th>ICD-10 Atypical Eating Disorder (AED)</th>
<th>Individuals with eating related difficulties who do not fulfil criteria for AN or BN.</th>
<th>exclusively during episodes of Anorexia Nervosa.</th>
</tr>
</thead>
<tbody>
<tr>
<td>DSM -5 -Eating Disorder Not Otherwise Specified (EDNOS)</td>
<td>The eating disorder not elsewhere classified category is for disorders of eating that do not meet the criteria for any specific eating disorder.</td>
<td></td>
</tr>
</tbody>
</table>
2.3 Impact of Eating Disorders

Family, relationships and physical health

The longer term psychological and social consequences may have a profound impact on the individual’s relationships, employment and parenting prospects (NICE, 2004). Eating disorders often have a negative effect on families, creating a stressful atmosphere and putting strain on relationships (Hillegé et al., 2005; Schmidt and Treasure, 2006). Ultimately this can lead to social withdrawal (Karatzias et al, 2009), for example avoiding family meal times and occasions like weddings and parties because of fear of gaining weight but also a way of hiding away from others. These individuals may lose their support network making recovery more difficult (Karatzias et al., 2009). Parents also report experiencing social isolation because of their perception that they were excluded from extended family members and peers (Hillegé et al., 2006), and because of lower perceived social support predicts poor family functioning (Dimitropoulos et al., 2008). In a qualitative study, parents perceived the Eating Disorders as having an adverse effect on their family and that their other children suffered from their lack of availability to provide emotional and instrumental support (Honey et al., 2006).

Emotional distress resulting from the Eating Disorders can also affect the individuals’ siblings on areas of their life such as school work and leisure time (Halvorsen et al., 2013). Siblings felt parents paid less attention to them during illness of the sibling with Eating Disorders and 24% felt parents had no time for them at all (Halvorsen, RO, and Heyerdahl 2013). Siblings also describe difficulties dealing with increased family conflict and increased responsibility for supporting and caring for their sibling with Eating Disorders (Areemit et al., 2010; Halvorsen et al., 2013).

Eating disorders affect not only the physical health of the individual but also impacts on their emotional wellbeing and strains relationships in particular with parents and siblings and since South Asian females are thought to have strong family
relationships this is an important area to research which will be discussed further in Chapter 4, qualitative study 3.

2.4 Epidemiology of Eating Disorders

The Department of Health (DoH) provides information on the hospital episode statistics but this only covers the UK National Health Service (NHS) and shows how many individuals received in patient treatment. This only captures a very small percentage of cases, since as much as 50% of the treatment is provided by private clinics and only the most severely ill people require in-patient care (Smink et al 2012).

Health statistics usually refer to prevalence and incidence rates, both measures of disease frequency, but slightly different. Incidence is the number of new cases in a given period, and prevalence, the total number of cases existing at any one time (Hoek & Van Hoeken, 2003). Since eating disorders can endure for several years, prevalence figures are slightly higher than incidence figures. Incidence figures can determine whether more people are developing the condition (Smink, Van Hoeken & Hoek, 2012).

A recent study employing the General Practice Research Database (GPRD), a large automated anonymised UK medical record data base containing information from General practices (GP’s) (Office for national Statistics 1998), data from 2000 to 2009 estimated that the incidence of diagnosed Eating Disorders was highest among girls aged 15-19 and the incidence rate of Anorexia Nervosa and Bulimia Nervosa was stable. However, the incidence of EDNOS increased in women aged 10-49 from 17.7 per 100,000 in 2000 to 28.4 per 1000,000 in 2009 although they could not determine whether the increase seen reflects community increase or better detection. The study estimated that 2 girls/1000 are likely to be newly diagnosed with an eating disorder in the UK. (Micali et al 2013). The main problem with the GPRD is that not all GPs record data onto this system and although anonymous, not all participants consent to their data being recorded. Also GPs may use different codes to represent
the same diagnosis and some diagnoses may be recorded differently from others (Khan, 2010).

The most reliable data available is that quoted in the National Institute of Health and Clinical Excellence guidelines on eating disorders (NICE 2004). NICE is an agency of the National Health Service charged with promoting clinical excellence in NHS service providers in England and Wales, by developing guidance and recommendations on the effectiveness of treatments and medical procedures. Table 2 below shows the figures for prevalence in cases per thousand of population. The incidence rate of eating disorders is commonly expressed in terms of per 100,000 persons per year (person-years). The study of new cases provides clues to aetiology (Smink et al 2012).

**Table 2: Prevalence in cases per thousand of population in the UK.**

<table>
<thead>
<tr>
<th></th>
<th>Anorexia Cases/1000</th>
<th>Bulimia Cases/1000</th>
<th>All eating disorders cases/1000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Females</td>
<td>4</td>
<td>20</td>
<td>24</td>
</tr>
<tr>
<td>Males</td>
<td>0.5</td>
<td>2.5</td>
<td>3</td>
</tr>
<tr>
<td>All Cases</td>
<td>4.5</td>
<td>22.5</td>
<td>27</td>
</tr>
</tbody>
</table>

This equates to an overall figure of 1.6 million people in the UK affected by an eating disorder.

Epidemiological surveys rarely mention the ethnic composition of their sample (Dolan 1991), which creates difficulties in determining the extent to which non-white females are affected by disordered patterns. Similarly Davis and Yager (1992) argue that, although there has been a recent increased awareness in eating problems among non-white groups, it is difficult to estimate the prevalence of these disorders among different racial and ethnic groups, due to a lack of good quality
epidemiological studies. This will be discussed in detail in Chapter 3, section 1 of the thesis.

2.4.1 Estimated prevalence

Prevalence figures for eating disorders have varied considerably due to measurement difficulties (Hoek & Van Hoeken, 2003), as well as due to lack of treatment–seeking behaviour of sufferers (Hudson, Hiripi, Pope, & Kessler 2007). A recent epidemiological study of (Smink et al 2012) of incidence, prevalence and mortality rates, found that while the overall incidence rate remained stable over the past decades, there has been an increase in the high risk group of 15-19 year olds. The authors argue that it is unclear whether this reflects earlier detection of cases or an earlier age of onset.

Table 3: Estimated ranges of lifetime prevalence rates of Eating Disorders in the general UK population.

<table>
<thead>
<tr>
<th></th>
<th>Anorexia Nervosa</th>
<th>Bulimia Nervosa</th>
<th>Binge Eating Disorder</th>
<th>Eating Disorder Not Otherwise Specified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence (%)</td>
<td>0.3% - 0.9%</td>
<td>0.9% - 15%</td>
<td>1.9% - 3.5%</td>
<td>2% - 5%</td>
</tr>
</tbody>
</table>

Source: Smink et al (2012)

Studies have attempted to estimate the prevalence of eating disorders (see table 3). According to the Health and Social Care Information Centre, 2,560 individuals were admitted to hospital in England for eating disorders between 2012 and 2013 (Health and Social Care Information Centre HSCIC, 2014), an increase of 8% from 2011 to 2012, when 2,370 hospital admissions were recorded. There is increasing evidence of eating disorders within Asian cultures, although information regarding specific incidence rates is limited (NICE, 2004).

Prevalence figures appear to be slightly larger in younger age groups, with adolescence being the peak period of onset (Striegel- Moore & Bulik, 2007). Furthermore, younger adolescents are more likely to display symptoms of Anorexia Nervosa, and older adolescents to display symptoms BN (Reijonen et al., 2003).
terms of ethnicity and culture, eating disorders have been predominantly reported in Caucasian females (Striegel-Moore & Bulik, 2004). South Asian females in the UK appear to have a higher prevalence of clinical bulimia and unhealthy eating attitudes in adulthood. McCourt and Waller (1996), in a review suggested that eating psychopathology among Asian women living in Britain is more likely to be a product of ‘culture clash’ during their childhood and adolescence. Ahmed et al (1994), conducted a quantitative study (using the EAT-26 and parental bonding instrument) in Asian and Caucasian school girls in Bolton, and found Asian girls had a greater level of bulimic attitudes than Caucasian girls. A significant part of this difference was due to the Asian girls’ greater levels of perceived maternal control. In an epidemiological survey of Bradford secondary schools, Mumford, Whitehouse & Platts (1991) found 7 Asian girls with BN (DSM-III-R), a prevalence of 3.4%; one Asian girl had AN. There was evidence that the Asian girls from the most traditional families had the highest risk of developing an eating disorder. Prevalence studies are considered in greater depth in Chapter 3.

2.5 Aetiology of Eating disorders

In trying to understand the development of eating disorders, investigators have focused on genetic, neurophysiological, psychological, familial and social factors; no single aetiological factor in isolation can account for the development of the disorder in an individual, nor can it be seen to account for the variation among individuals (Cooper, 1995). These factors in combination, of risk and protective factors, are all thought to play a role in the origin and maintenance of the disorders, and most importantly determine whether an individual recovers.

2.5.1 Genetics

There is some evidence to suggest that eating disorders have a biological aetiology. Anorexia has been found to be partly genetic and run in families (Klump et al, 2000; Rutherford et al, 1993). Theander (1970) was the first to note increased prevalence of anorexia nervosa in the sisters of sufferers (Rutherford et al 1993). Studies of families of anorexia patients (Strober et al 1990), and twin studies (Walters et al
1999, Bulik et al 2000) concluded that there are shared as well as unique genetic influences on major depression and both anorexia and bulimia. A number of factors have been identified; genetic predisposition to an imbalance in serotonin (a neurotransmitter involved in mood and brain function); an imbalance in serotonin that is brought about by severe weight loss, fasting, over-exercise, or vomiting, and reduced blood flow to the temporal lobe (Polivy & Herman (2002). In the 1980s, twin studies in anorexia nervosa led to radical re-evaluation of the long term emphasis on the social and cultural explanation of eating disorders, and it is now accepted by most researchers that eating disorders have a genetic component (Bulik et al, 2000).

2.5.2 Cultural influences on development of Eating Disorders?

Eating disorders are still more common in Western cultures and more common in girls and women than boys and men (Miller & Pumariega, 2001). It has been argued that eating disorders in particular Anorexia may be culture-bound in that it has no physical mechanism and arise only from the emerging characteristics of one’s culture (Prince 1985).

Cultural believes and attitudes have been identified as a significant factor in the development of Eating Disorders, in particular the increasing idealisation of a body type in the Western society is recognised as a possible factor in the development of Eating disorders (Miller & Pumariega, 2001). Keel and Klump (2003) looked at whether eating disorders were present in other sociohistorical and cultural contexts in order to determine whether Anorexia Nervosa and Bulimia Nervosa are “Culture Bound.” Their research suggests that anorexia is not culture bound (i.e. it can occur in the absence of certain aspects of culture) while bulimia is (i.e. it only/primarily appears in certain cultural contexts). Whilst the physical presentation of the disease may be similar, the cognitions of the patients differed cross cultures. Prince (1985) suggested that as the reach of Western cultural norms becomes more influential around the world, that eating disorders would become more common in places that had previously been considered immune.
There is significant evidence of a cultural shift in Western societies towards a preference for a thinner female's body form (Shroff & Thompson 2004) but no agreement as to why this has occurred or whether it is fundamental to the aetiology of eating disorders. A number of general characteristics have been identified: improved nutrition, increased wealth, lower mobility rates, reduced fertility, later age of marriage/long-term relationship and an increase of women in the labour market against men (Littlewood 2004). This has led to greater equality and perhaps increasing identity with men, resulting in a different “fit” between social roles, goals, class status, child bearing, and body image, with less emphasis on women’s maternal and domestic roles resulting in generational distinctions (Giddens 1991); and even a possibly related shift in male sexual attraction to an androgynous and “younger” female body, perhaps as a response to feminism (Bordo 1993; Littlewood 2002).

Thomas (1990) stated a child’s body image is shaped by what the child overhears from family members, peers and by the child’s ideas about the current cultural image of an ideal body. Yet the children of immigrants from Eastern countries are also affected because although sharing their parents’ physical and psychological characteristics and heritage, they may be exposed to a different and conflicting set of socio-cultural norms and ideals coming from the surrounding Western culture.

Research examining immigrants to a new culture also suggests that, in addition to cultural background, consideration should be given to current residency and acculturative status when attempting to understand relations between culture and eating problems (Davis & Katzman, 1998; Nasser & Katzman, 1999). Cross cultural epidemiological data, supports the acculturation of eating disorders with Western cultural exposure, these occur through acculturation, which is defined as the process of cultural change and psychological change that results following meeting between cultures (Sam & Berry, 2010), associated with both migration and in country rapid social and economic development (e.g., Becker 2004; Becker et al. 2002, 2010a; Nassar et al. 2001).

Bhugra (1996) highlighted that the feelings of depression are universal, but the clinical features are different across cultures, and a client’s perception and
communication about symptoms is influenced by culture, as is the interpretation of the clinician.

In relation to this cultural shift, an overarching characteristic of the role of autonomy and self-expression in eating disorders has been termed as “modernization” (Deutsch 1991). Moreover with increasing global modernization, there is among the educated, a modern culture that touches all countries and which is beginning to override old traditions and place a more powerful emphasis on physical appearance (Mahmud & Critten 2007). Mumford, Whitehouse and Choudry 1992 found that Asian females living in UK show greater levels of eating psychopathology than Caucasian girls, and Asian females scoring high on an EAT questionnaire were associated with a more traditional orientation and not with greater westernization. Therefore this data may suggest the importance of ethnic and cultural factors as determinants of eating problems.

A recent review found substantial evidence that there is an association between cultural change and Eating Disorder psychopathology. However, both greater and lesser acculturation have been identified as risk factors for the development of an Eating Disorder, and this varies depending on the group as well as how acculturation and culture change are conceptualised and measured, (Eli et al, 2015).

Countries like Pakistan and India have experienced rapid socio-economic changes, such as westernisation in dress and new concepts of beauty and femininity have gradually crept in from the West (Candela & Saxene 1990). They have now established dieting culture and with similar average body mass to Caucasian females, particularly indicated in British Asians, concern with body fatness does correlate with Eating Attitude Test (EAT) measures (Mumford 1991). Among psychiatric disorders, Eating Disorders (EDs) are characterised by the degree to which they are thought to be shaped by social and cultural phenomena. (Nasser 2003). These changes are reflected in Bollywood films and Asian TV dramas (Kapadia, 2009) and the incidence of Eating Disorders within these communities may be consequently rising. This will be discussed below in Chapter 3, systematic reviews study 1 and 2.
As a review of qualitative studies of Asian females with eating disorders has not been carried out before, chapter 3 section 2, will explore this through a systematic review of qualitative studies on the experiences of South Asian females with these conditions.

2.5.3 Peer influences

Peers could represent a key socio-cultural risk factor for eating disorders, as Shroff and Thompson (2006a) suggested that friends and peer influence could pose potential risks for body image, eating disturbance and self-esteem. Furthermore, Stice (1998) argues that adolescents have felt greater pressure to be thin from peers than from other sources of influence, such as family and the media. He also found that it was peer influences that predicted bulimic behaviour in his sample of adolescent girls.

2.5.4 Family influences

The role of negative family relationships has long been associated with Western understanding of the development and maintenance of eating disorders (Laliberte et al 1999). Bruch (1970) emphasized the importance of the family’s influence on eating disorders by highlighting that treatment was likely to fail if family was not involved. Later Minuchin et al (1978) highlighted a group of family system characteristics which they believed were representative of families with a patients with Anorexia Nervosa, this was termed as models of Family systems and family theory and the psychosomatic family. These characteristics were: enmeshment, over-protectiveness, rigidity, avoidance of conflict and lack conflict resolution. Self-starvation might simply be the most accessible way of generally expressing distress and soliciting help from others, particularly parents and family members.

Family dynamics (Lock & Grange 2005) can be a catalyst to both the development of an eating disorder or interference with recovery. This can be through poor communication and support within the family, lack of emotional bonding and dealing with feelings within the family, family values that magnify the importance of appearance, sexual or physical abuse, lack of a focus on the importance of family
life, dysfunctional body image and the dieting behaviour of parents (Gowers & Shore, 2001).

It can be argued that communication, bonding and ‘dealing with feelings’ are difficult to measure. Hill and Franklin (1998) found girls to be engaged in more unhealthy weight control practices when their mother was dieting and was overly concerned with their weight and shape. Furthermore, Pike and Rodin (1991) found adolescent girls exhibiting greater eating disturbances when their mothers were more critical of their weight and appearance than girls without disturbed eating behaviours. Additionally, Attie and Brooks-Gunn (1989) found that vulnerability to developing eating problems amongst adolescents was associated with a less cohesive and less supportive family. Familial unhealthy eating habits and undue concern about the importance of weight and shape have also been described in the family members of those with eating disorders and may contribute to weight and shape concerns in vulnerable adolescents (Gowers & Shore, 2001).

McCourt and Waller (1995) found that high levels of perceived maternal control partly explained the unhealthy eating attitudes among Asian females. This was particularly stronger in older females, suggesting a development trend through adolescence. The main reason for this, they argued, was that older females attempt to establish greater levels of peer identification and self-control, which are appropriate to their age in the Western culture but which may conflict with their parents' view. Similarly, Ahmed, Waller and Verduyn (1994) also argue Asian females have more unhealthy eating attitudes than Caucasian females, suggesting that difference is due to “Cultural conflict”, but suggest that this term needs to be operationalised by determining the underlying practical and psychological mechanisms. They found Asian females had greater levels of bulimic attitudes than Caucasian females and argued that the significant part of this difference was due to the Asian females’ greater levels of perceived maternal control.

2.5.5 Media influences

Orbach (1993) argues that a key social influence seems to be that of the media. “Perceived pressure to be thin” does appear to predict dieting and eating pathology
Today most women on television are much thinner than their predecessors in earlier decades and also much thinner than the average women (Gorden, 1990). Field et al (2001) found that both adolescent boys and girls attempt to look like their same-sex idols in the media resulting in weight concerns and regular dieting behaviour. It is the Western culture of the “thin ideal” that the mass media encourages, which leads adolescent girls to also form unrealistic ideals about their body weight and shape (Field et al, 1999). This internalisation of the thin ideal can be a risk factor for the development of eating disorder pathology (Thompson & Stice, 2001; Shroff & Thompson, 2006b).

There has been no similar evidence yet presented which points to changes in the shape and weight of significant images in the Asian media leading to the development of eating disorders, however similarly, there have been recent changes in the shape and weight of significant female images in the Asian media, for example contemporary leading Indian film actresses appear much slimmer and are more likely to be dressed in Western clothes, than the more curvy figures dressed in traditional clothing which characterised these roles up to the early 1980’s (Shroff & Thompson, 2004). This may be due to Asian countries undergoing rapid social and economic changes, thus having increasing contact and influence from Western culture (Hill Drapes & Stack, 1993). It is highly likely that this portrayal of thin females may influence British Asian females to adhere to pressure to be thin, not only from the Western media but also from the Asian media (Wooley & Wooley, 1980), this will be explored further in Chapter four of the thesis.

2.6 Treatments of Eating Disorders

Treatment for Anorexia Nervosa presents significant financial implications for healthcare services due to the need for repeated episodes of hospitalisation and long-term health care (Office of Health Economics, 1994). Response to treatment is problematic as less than half of individuals fully recover and approximately 20% experience chronic symptoms (Seinhausen, 2002). Those in recovery tend to present again with poor weight maintenance after treatment, while there is an increased risk for relapse and readmission amongst those treated as in-patients (Vandereycken,
Furthermore, drop-out rates are high, suggesting dissatisfaction with services and/or treatment (Mahon, 2000). Steinglass et al (2011) argued that high relapse rates presented by those treated for anorexia signal that acute weight restoration is only the first step and that there is a need to increase understanding of the factors associated with the persistence of dysfunctional eating behaviour after the weight restoration.

The National Health Service (NHS) guidance on the treatment of eating disorders (NICE, 2004) promotes psychological approaches as a treatment of choice for all diagnostic categories of eating disorder and highlights the importance of patient and career satisfaction in the assessment of treatment effectiveness for eating disorders. The guidance recommends that most individuals with Anorexia Nervosa should be managed on an outpatient basis within services competent in assessment and management of physical risks involved in this condition. Where inpatient re-feeding is required, treatment should be delivered alongside psychosocial interventions. The guidance promotes evidence-based self-help approaches as an initial treatment option for Bulimia Nervosa, therapeutic interventions such as cognitive behavioural therapy (CBT), interpersonal psychotherapy (IPT) or alternative treatments such as family therapies are recommended as secondary treatment options (NICE, 2004). However, as the guidelines stress, there is limited evidence for their effectiveness. If outpatient therapy is not successful, or if the person deteriorates, then combined therapies for example, individual and family therapy, day care or inpatient treatment are recommended. Medication is not recommended unless it is for co-morbid conditions such as depression or OCD, as there may be problems with drug absorption and toxicity due to starvation, vomiting, dehydration and over hydration in this clinical group (NICE, 2004).

2.6.1 Cognitive Behaviour therapy (CBT)

Cognitive Behaviour Therapy (CBT) for eating disorders (CBT- Bulimia Nervosa CBT-BN, Fairburn, 1981; CBT-Enhanced, Fairburn 2008) aims to modify maladaptive beliefs and behaviours that continue the cycle of eating disordered attitudes and behaviours. Interventions includes the monitoring of food intake with
the aim of establishing normal eating patterns, setting behavioural experiments to overcome anxiety provoking situations, and cognitive restructuring through challenging rigid unhelpful thoughts regarding perfectionism, self-criticism (NICE, 2004). NHS treatment guidance suggests individuals should be offered between 16 and 20 individual sessions of CBT over a period of four to five months (NICE, 2004). For those with bulimia, CBT is reported to be the most effective treatment (Wilson, Fairburn & Agras, 1997).

2.6.2 Interpersonal Psychotherapy (IPT)

Interpersonal Psychotherapy (IPT) aims to support individuals to identify and address interpersonal problems. NICE guidance (2004) highlights that IPT may be presented as an alternative to CBT. However, individuals should be aware that comparable treatment effects may take up to seven months longer than CBT. However Hay et al (2009) assessed effectiveness of a large number of psychotherapies, including Interpersonal Therapy (IPT) and Cognitive Behavioural Therapy (CBT). They found all the therapies were equal to one another in their efficiency and more research was needed before they could recommend one over the other.

2.6.3 Family therapy

It is important to look at the family dynamics and the relationships within the family as a system, in order to understand what conflicts may be provoking eating pathology (Minuchin, Rosman & Baker, 1978). Nice (2004) also recommends that “Family members including siblings should normally be included in the treatment of children and adolescents with eating disorders” (P63). Although siblings are invited to Family Therapy they often do not attend (Abrams 2009). This can relate to parental concern about siblings and the impact of taking time away from other aspects of their lives, such as school and social activities (Bryant-Waugh and Lask, 2007). This can also be a result of parents aiming to protect both siblings; the privacy of the sibling diagnosed and the protection of the sibling from the situation (Abrams, 2009). However, siblings
themselves may be reluctant to attend (Honey, Clake, Halse, Kohn, & Madden, 2006), although the reasons for this have not been outlined. Furthermore, few studies have explored the experiences of siblings, as they may be considered at risk of being affected by their sibling's mental health (e.g Abrams, 2009).

Fisher et al (2010) examined four family-based treatment approaches: Family-Based Therapy (Lock et al., 2005, 2006), Strategic Family Therapy (Madanes, 1981), Structural Family Therapy (Minuchin, 1978), Systems Family Therapy (Palazzoli, 1978) and other approaches in relation to psychological and pharmacological intervention. It was concluded that there were no substantial differences in the efficacy of different treatment approaches in treating anorexia nervosa. This suggests that although different psychotherapies seem to lead to some improvement in disordered eating symptomology, they still need to improve as there is low to moderate efficacy of such treatments.

It can be suggested that talking therapies are largely dependent on the ability of the patient to self-reflect and identify connections between cognitions, emotions and behaviours, but if individuals are unable to describe their experience effectively then it prevents them from fully responding and benefiting from these therapies (Ogrodniczuk et al, 2010).

Existing research exploring patient perspectives of eating disorders has mainly focussed on experiences of having an eating disorder and the identification of recovery factors, with perceptions of treatment and services remaining largely neglected (Vanderlinden et al 2007). There remains a growing need to explore perceptions of treatment quality, particularly for anorexia nervosa, to address difficulties with treatment adherence and outcome (De la Rie et al 2008).
2.7 South Asian females and Eating Disorders

2.7.1 Definition of ‘British South Asian Female’ in this study

It needs to be clarified what the term “British South Asian Female” is, in relation to this research study. When we talk about South Asian women it is important to note that they are not a homogeneous group. Diversity needs to be recognized as arising from location, class, religion, language, cast sect and culture (Brah 1992). The actual definition of the term South Asian varies depending on the study, with some studies defining it as those who descend from India, Pakistan and Bangladesh (eg Pandya & Herlihy, 2009) where as others incorporate these groups plus Sri Lankans and East Africans (Bohpal 2004, Marchall & Yazdani, 2000). For the purposes of this thesis the term South Asian is confined to young women of primarily Indian, Pakistani, or Bangldeshi heritage who are living in UK. It needs to be recognized that Asian females come from a wide and varied complex culture; (culture can be defined as the customs, morals, knowledge and values of a particular social group). Their position within this culture needs to be taken into account in relation to their health (Bhopal 1991).

2.7.2 Emotional distress and eating disorder

Much of the psychological literature with reference to British South Asian females is on mental health, suicide, self-harm and depression (Anand & Cochrane 2005). Furthermore, Reese (1982) focused on first generation of Asian woman in Britain and argued like many minority women who are also immigrants to the UK, must adjust to a dramatically different way of life; these factors are thought to lead to high rates of depression in these groups of women. Studies which focused on second generation of British Asian women found that problems experienced include culture and identity problems, integral conflicts and depression (Scotto et al 1990). Others like Owen and Raleigh (1990) found that those Asian women holding non-traditional values, who as a result experience conflict with their parents, scored higher on suicide ideation compared to Caucasian counterparts. Also, there was a high score on
suicide intent among newly married Asian females related to the pressures of cultural expectations for them to conform to set roles. Furthermore, Littlewood et al (1991) argue that there is a link emerging between lack of provision, lack of understanding and an increase in social distress.

The literature therefore, demonstrates that South Asian females do experience emotional distress, for many different reasons. Although traditionally, depression, suicide and self-harm are seen as significant problems for South Asian women (Anand & Cochrane 2005), the literature also suggests that the eating disorders are now also becoming prevalent among South Asian females (Cummins et al, 2005). Although these studies did not ignore cultural and community backgrounds, they do not go into a great deal in this area because these studies rely upon the use of quantitative method of research and data in a quantifiable form tends to lose context and integrity of data (Banister, et al, 1994). Qualitative methodology on the other hand, allows a large volume of data to be obtained from a limited number of individuals (Walker 1985). Additionally, there seems to be little research about cultural stress among Asian females and their eating habits. For this reason the researcher feels that it is important to understand the cultural stress that Asian females may experience, in order to gain a better understanding of the main reasons why eating disorders are apparently higher among South Asian females.

Despite rich diversity in the UK, there are often stereotyped views of what Asians believe and how they behave. Ultimately, it can be argued that these stereotypes become incorporated as ‘fact’ and have the potential to misdirect diagnose and therefore, also misdirect treatment pathways (Burr, 2002). This potentially means that many mentally distressed Asian women may be failing to get adequate help because there so little understanding of their particular backgrounds and individual needs.
2.8 Accessing mental health services

Studies have shown that Eating Disorder patients are reluctant to disclose their symptoms and seek help, both at the primary care level and at specialised levels (Fairburn & Cooper, 1982, Johnson et al, 2001) or fail to engage with treatment once they have been referred (Bell, 2001; Palmer et al 2000). Under-detection of eating disorders in a clinical setting is common because people with Eating Disorders often present emotional difficulties rather than seeking treatment for their disordered eating patterns (Sim et al 2010). For example, Meyer (2001) found that 49% of the 238 high school females exhibited an eating disorder through screening and help-seeking questionnaires, but only two of these participants were receiving psychological treatment. Participants’ reasons for not seeking treatment included not feeling as though they had a problem, feeling as though the problem was not worrisome enough and not wanting others to know. Furthermore, health care professionals may only detect an Eating Disorder following a detailed medical and psychological assessment (Walsh 2001).

A recent study by Becker et al (2010) identified cultural and societal-based barriers to seeking treatment in an ethnically diverse sample of participants. A range of ethnicities were represented in their study and they also noted how stigma, shame, social, stereotypes, social norms and socio-economic distance formed culturally based barriers to care. Themes emerged for both minority and non-minority groups but there were differences in their experiences, for example both groups of participants reported that social stereotypes affected treatment; a Caucasian participant reflected on how her help-seeking was facilitated by the social stereotype of mostly young Caucasian woman being affected by eating disorders, whereas two African-American participants described how they perceived their symptoms were dismissed by clinicians because they did not fit the racially-based stereotype.

In relation to South Asian females and eating disorder services in the UK, studies have found under-referral of South Asian females to eating disorder services. For example Waller et al (2009) examined referrals to two UK eating disorder services in
ethnically diverse catchment areas, where 12% of the 648 patients were from ethnic minorities. Using the UK census data 2001, they found there were a disproportionately large number of Caucasian patients compared to the percentage of Caucasians in the local population, whereas the number of ethnic minority patients was low. Also compared to Caucasians, individuals from the ethnic minority groups are much less likely to seek treatment for psychological problems, including access to care for psychiatric services (Borowsky et al 2000).

Ratan, Gandhi and Palmer (1998) examined a register of referrals for eating disorders over a ten-year period from July 1984 to June 1994 of Asian residents in Leicester. They found that Asian women with eating disorders were referred less often than their non-Asian counterparts and argued that this might be due to a number of reasons; lower prevalence, variable or high threshold filters to secondary care for such women, or it may be that people of Asian background are even less likely to want or to be thought appropriate for referral.

Data from the Health and Social Care Information Centre (HSCIC) for the year 2012-2013 shows hospitals in England dealt with 2,560 admissions an, increase of 8% on the 2,370 cases in the previous year. Table 4 shows a breakdown by ethnicity count of finished admission episodes (FAEs) which is the period of inpatient care under one consultant within one healthcare provider. FAEs are counted against the year or month in which the admission episode finishes, as admissions do not represent the number of inpatients, as a person may have more than one admission within the period.
Table 4: Count of finished admission episodes (FAEs) with a primary diagnosis in NHS hospitals in England of an eating disorder for the year 2012-2013.

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Count of Finished Admission Episodes (FAEs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian</td>
<td>86</td>
</tr>
<tr>
<td>Black</td>
<td>45</td>
</tr>
<tr>
<td>Chinese and other</td>
<td>44</td>
</tr>
<tr>
<td>Mixed</td>
<td>36</td>
</tr>
<tr>
<td>Not Stated</td>
<td>141</td>
</tr>
<tr>
<td>White</td>
<td>1986</td>
</tr>
<tr>
<td>Unknown</td>
<td>43</td>
</tr>
</tbody>
</table>

Source: Hospital Episode Statistics (HES), Health and Social Care Information Centre (2014)

In addition, research carried out by Soni Raleigh et al (1992) identified trends in national mortality rates which demonstrate a higher rate of suicide in women from the Indian subcontinent. The standardised mortality ratio (SMR) is particularly raised for the age group 15 to 24 years, where it is more than twice the national rate.

2.9 Culturally competent mental health services

In reflection of an increasingly diverse population in particular, South Asian populations constitute 4% of the population (Bowl, 2007), and a better understanding of the health inequalities across a range of minority groups, the pressure is on to deliver culturally competent services (Crandall, George, Marion, & Davis, 2003). In accordance with the need to train health professionals with the ability to provide quality care for a diverse population, statutory/accreditation bodies and government bodies worldwide now require cultural competence to be addressed (General medical Council, 2009; Liaison Committee on Medical Education, 2010).

Large scale migration from South Asia to Britain began after World War II and continued through the economic boom and labour shortage in the 1950’s and 1960’s. The majority of immigrants were from Gujrat and Punjab from India, Mirpur in Pakistan and Sylheti in Bangladesh (movinghere.org.uk). At least three generations
of South Asians now live in Britain and the 2001 census showed that over half of the minority ethnic population in the UK is of South Asian origin (Statistics.gov.uk). Indians were the largest minority group, forming 22.7 per cent of the total population, 16.1 per cent were Pakistanis and 6.1 per cent were Bangladeshis. South Asians in Britain come from a wide range of communities with different religions, languages, cultures and beliefs and within each community, people vary as to their social, financial and educational background and their aims and attitudes.

In order to improve the cultural competence of mental health services the government has introduced initiatives such as the Department of Health (2003) report “Delivering Race Equality: A framework for Action”, in which the importance of addressing the mental health needs of Black and minority ethnic groups in Britain was highlighted and targeted as a priority in the provision of appropriate mental healthcare within the National Health Service.

South Asians’ vulnerability to mental health problems, along with levels of cultural and institutional exclusion/participation (Chakraborty 2002, Bowl 2007) have been linked to their experiences of life in Britain furthermore their sense of identity and belonging, cultural differences, prejudice, racism and alienation in British life are all reflected in their socio-economic status. There is now considerable evidence suggesting a higher prevalence of mental health problems among these women in certain domains such as, depression, suicide, self-harm, and eating disorders (Bhugra & Bhui, 2003; D’Alessio & Ghazi, 1993; Fazil & Cochrane, 2003). The household survey of 10,000 adults commissioned by the Department of Health date revealed that depression appeared to be twice as prevalent among ‘Asian and Oriental’ women compared to white women (OPCS, 1995, p. 34).

Hernandez et al (2009) carried out a literature review of organisational cultural competence in the United States and found that ethnic disparities in access to mental health were driven by incompatibility between available services and the cultural and social context of the people they served. They proposed a model of cultural competence that requires compatibility between four factors: community context, cultural characteristics of the population, organisational infrastructure and direct
service. Since they did not report their literature search strategy or record papers yielded from the search, it is therefore unclear whether their model arose from the literature or they presented literature that supported a pre-exciting literature. However their model does address the need for a multi-level, multi-factorial approach to developing and delivering culturally competent mental health services.

Ideally, treatment for an eating disorder should address both the physical and psychological aspects of the eating disorder. A purely medical approach to treatment of eating disorders (one that focuses on physical consequences and food) is unlikely to address the underlying psychological causes, or result in long-term recovery. A multidisciplinary approach to treatment is optimal (Hugo et al 2000); a general practitioner, a dietician, and a psychotherapist are usually involved in the eating disorder treatment team.

In relation to psychiatric services, Bhui and Sashidharan (2003) highlight the ethnic inequalities in access to specialist care and differences that have been documented in assessment and management practices; as well as the voiced dissatisfaction by numerous minority ethnic mental health service users (Raleigh et al, 2007). Major disparities in service experiences and outcomes cannot be attributed to ‘special ethnic needs’ or behaviours and professional practices that serve to marginalise and disadvantage people of minority ethnicity.

A growing literature on ethnic disparities in health care access and health outcomes highlights the importance of clinicians understanding the impact of socio-cultural background on illness presentation and help-seeking behaviour for improving the quality of care delivered, (Betancourt 2004). Furthermore, data also suggest, (at the level of a trend) that ethnic minority individuals with eating and weight related symptoms or concerns may be less likely to seek treatment than non-minority individuals with similar concerns, (Becker 2003).

Recognition of, and response to an eating disorder is likely to relate to both clinical explanations about prevalence and presentation of the illness as well as patient factors relating to help-seeking and distress. Therefore, identification of differences
in the pattern of symptoms and articulation of distress across diverse populations can be useful in training clinicians to deliver culturally competent care (Lopez 1989).
2.10 Summary of chapter

Eating Disorders are problematic conditions comprising of Anorexia and Bulimia and are most commonly (but not exclusively) seen in young women, hugely impacting on both the individual, their family and society. They are challenging to diagnose and prevalence is increasing. Also cultural factors such as family and media influences are key to aetiology, and research to date has largely been done on Western Caucasian females.

Despite increasing recognition of the prevalence of eating disorders among South Asian females, not only those living in Western countries but also among those living in their country of origin, research have largely omitted the study of this population. Women with Eating Disorders struggle to access mental health services and this is particularly true for BME groups, probably because of a number of factors such as treatment services not meeting the needs of these groups of women. In order to develop culturally sensitive services, research is needed on the scale of the problem (i.e. by conducting a systematic review of the prevalence of eating disorders among South Asian females (study 1) in the UK and the Indian sub-continent) and the experience of the problem, through conducting a systematic review of qualitative study (study 2) of South Asian females. In order to expand on these reviews the researcher conducted a qualitative study (study 3) of the experiences and perceptions of South Asian females with eating disorders, family members and health care professionals.

The overall aim of this research is to understand the health experiences and accessing services outcomes of British Asian females suffering from eating disorders and also to understand the barriers to effective engagement with services (what family and cultural barriers are there and how can services address them). At the same time it will seek to understand the ability of organizations and professions to meet the needs of these individuals.
Section 2

Systematic reviews of eating disorders among South Asian females
Chapter 3

**Study 1** - A systematic review of epidemiological studies into the prevalence of eating disorders among young South Asian females in the UK and the Indian subcontinent.
3.1 Overview

Measuring prevalence is important as it indicates the demand for care so is an important way of planning health care facilities (Hoek & Hoeken, 2003). Case detection through a two-stage screening approach is the standard procedure to estimate the prevalence of eating disorders (Williams, Hand & Tarnopology, 1980). At stage-one, a screening questionnaire is administered to a large population to identify an at-risk group and in stage-two, definite cases in the at-risk group are established on the basis of an interview (Fairburn & Beglin, 1990).

Although there has been a recent increase in awareness of eating disorders among non-white groups, the true prevalence of eating disorders among South Asian females is likely to be underestimated due to both the reluctance of people to report them, and also inaccurate recording of ethnic breakdown (Dolan 1991). Prevalence rates of eating disorders have shown to vary among diverse ethnic groups. For example, within the US, estimates of anorexia and bulimia range from 1% to 4%, depending on age, ethnicity, and location of the individual (Dolan 1991). Estimates of eating disorders in Asian countries range from 0.002% to 3.2% (Nasser, 1994; Lee, 1993).

A review by Cummins et al (2005) focused on the evidence for eating disorders in ethnic minorities, examined studies conducted in Asia including Pakistan, India, Japan, Hong Kong, and China and Western countries including UK and the United States. They found that, overall; the prevalence rates of diagnosable eating disorders were lower in the non-Western countries. However, studies of British South Asian females find significantly higher levels of eating disorder symptoms (Furnham & Patel, 1994), particularly bulimia nervosa, compared to Caucasian females (Mumford, Whitehouse, & Platts, 1991). Cummins et al (2005) argue that these findings are inconsistent and furthermore, there were methodological limitations to these studies.
In order to develop culturally sensitive services, current research is needed to determine the scale of the problem within these groups of women. Therefore a systematic review of studies into the prevalence of eating disorders among South Asian females particularly of Pakistani, Bengali and Indian ethnicity in the UK and the Indian subcontinent was conducted in order to aid our understanding of the prevalence in this population, and also highlight possible associated factors.

**Aim of the review**

This systematic literature review aimed to:

- a) Review evidence of the prevalence of eating disorders among South Asian females in the UK and the Indian subcontinent
- b) Consider the possible associated/aetiological factors revealed by these studies
- c) Review the methodology employed within studies included in the review
- d) Consider the quality of included studies.

**3.2 Methods**

The review was planned and reported using the Meta-analysis of Observation Studies in Epidemiology (MOOSE) guidelines (Stroup et al 2000) for systematic reviews of observational studies. Systematic reviews are distinguished from conventional literature reviews in the fact that they conform to the methodological standards used in primary research, namely transparency, rigour, comprehensiveness, and reproducibility (Briner, Denyer, & Rousseau, 2009; Denyer & Tranfield, 2009; Littell, Corcoran, & Pillai, 2008). For quality assessment of this review, a quality criteria check table was developed (see Table 6) by utilising relevant items from the STROBE (The Strengthening the Reporting of Observational Studies in Epidemiology) checklist (see Appendix 1, Vandenbrouke et al 2007) of items to be included in reports of observational studies as it is widely used as guidance for assessing the quality of epidemiological studies (Zaccai 2004, Vandenbroucke et al 2007).
A ‘cultural quality check’ was also considered important. This is where each reviewed study is examined in terms of ‘cultural quality’, and specifically, in relation to the whether it meets the needs of South Asian participants. This should be part of any study aiming to research different ethnicities and cultures, but particularly in this review where all of the studies included South Asian participants. Leininger (1995) points out, without cultural awareness, researchers tend to impose their beliefs, values and patterns of behaviour upon cultures other than their own. Papadopoulas (2001) believes that culturally incompetent research is bad research, is unethical because it can waste resources and may lead to inappropriate resources being used. Papadopoulas & Lees (2001) argue that most countries are now becoming multi-ethnic which presents considerable challenges for health care researchers, where there is a need to be responsive to the different needs, experiences, values and beliefs of ethnically diverse populations. Table 7 comprises 12 areas thought to be important in assessing cultural quality. The first nine were taken from an unpublished PhD thesis (Waquas, 2010) and the final three were included by the author, following a scoping review of the literature and discussion with supervisory team.

3.2.1 Search terms for a systematic review of literature

The search terms listed in Figure 1 ($= with wild cards when necessary) were used when devising search strategies for electronic databases. The selection for search terms was undertaken with advice from literature search services at the University of Manchester Library and a review of search strategies developed for ethnic minorities from other publications covering coronary heart diseases and mental health (Bhopal 2000, Bhui et al 2003). Studies to be considered for retrieval were recorded on Endnote, (EndNote is a commercial reference management software package, used to manage bibliographies and references when writing essays and articles. It is produced by Thomson Reuters, Endnote X5 June 2011). To ensure no relevant studies were missed the researcher also hand-searched the references lists of these studies.
Search term Phase 1

Search term 1-6: The eating disorder search terms that were used are covered by ICD 10 and DSM IV. These terms have also been used in South Asian developing countries and ethnic minorities.

Search term 8-21: Ethnicity search terms were selected to include as any variations in the way ethnicity is reported in published research. Names of individual South Asian countries were also used as search terms.

Search term 23-33: young females, to select studies that included young females.

Search term 35-47: epidemiological, to ensure only epidemiological studies were selected.

Search term Phase 2

Combining search terms:

To combine each term “OR” was used for example (or/1-6, or/8-21, or/23-33, or 35-47) and to combine these “AND” was used for example 7and 22 and 34 and 48.
Figure 1. Key search terms for epidemiological systematic literature search

1. eating disorder$.mp.
2. anorectic.mp
3. bulimi$.mp.
4. anorex$.mp.
5. binge eating.mp.
6. (eating disorder$ or bulimi$ or anorectic or anorex$ or binge eating)
7. or/1-6
8. gujrat$.mp.
9. pakistani$.mp.
10. india$.mp.
11. bangladesh$.mp
12. punjab$.mp.
13. bangal$.mp
14. kashmir$.mp.
15. south asian$.mp.
16. mirpur$.mp.
17. south asian.mp.
18. asian$.mp.
19. ethnic$.mp.
20. ethnic minority$.mp.
21. ethnic group$.mp.
22. or/8-21

1-6

23. schoolgirls$.mp
24. female$.mp.
25. women.mp.
26. young.mp.
27. teen$.mp
28. child$.mp.
29. adolescent$.mp.
30. or/23-33
31. juvenile.mp
32. young adult$.mp
33. or/23-33
34. cohort study.mp.
35. prospective study.mp.
36. retrospective study.mp.
37. longitudinal study.mp.
38. follow-up study.mp.
39. case-control study.mp.
40. epidemiological study.mp
41. observational study.mp.
42. population study.mp.
43. cross-sectional study.mp.
44. prevalence.mp.
45. incidence.mp.
46. epidemiology.mp
47. or/35-47
48. or/35-47
49. and 22 and 34 and 48

8-21

South Asian
Countries

Search terms

terms for ethnicity

Epidemiological

female & age

Search terms

7 and 22 and 34 and 48
3.2.2 Literature search procedure

Relevant studies were identified through search terms in PsychINFO, Medline, CINAHL & EMBASE (1806 – 2014). Additional searches were conducted of previous reviews and key references, and relevant journals (e.g. International Journal of Eating Disorders & Journal of Health Psychology).

Electronic search strategy

A) Medline
B) CINAHL (cumulative index to nursing & allied health literature)
C) PsycInfo EMBASE
D) Google search first 100 references
E) Hand search: reference lists of all included studies

Inclusion Criteria

Studies were included if they met the following criteria:

- Studies must report prevalence of eating disorders in South Asian females particularly of Pakistani, Indian and Bengali origin.

- Studies include participants within UK or Indian subcontinent (particularly Pakistan, India or Bangladesh)

Exclusion criteria:

Studies were excluded for the following reasons:

- Clinical/case studies

- Studies that examined aetiology and/or psychopathology within samples but were not studies of prevalence

This was done to ensure that the included studies employed a robust design, their results were valid and a homogeneous set of studies were reviewed.
3.2.3 Process of data extraction

Selection procedure
The inclusion and exclusion criteria for screening and selection were driven by the main aim of the review. Inclusion and exclusion criteria were applied successively to titles abstracts and full text. Full reports were obtained for those studies that appeared to meet the criteria. The initial selection was broad to ensure that as many studies as possible were assessed as to their relevance to the review. The numbers of articles included or excluded at the various stages were noted (see figure 2).

The screening & selection process.
Studies were selected for retrieval from their titles and abstracts. Full texts identified in electronic searches were approved through an inter-rater reliability check which was conducted on the final thirteen studies in agreement with the researcher and supervisor. However abstracts and titles that clearly had no relevance to the aim of the review were excluded by the researcher only.

3.3 Results

The searches within the four databases identified 471 papers. Thirteen additional papers were identified through hand searches. After removing duplicates, 247 papers remained and after removing those not meeting criteria, 13 were included in the review (see Figure 2 for selection of papers). After inclusion and exclusion criteria were applied, 232 studies were excluded leaving 15 and a further 13 were identified by hand searching the reference lists. The full text of these 28 studies (please see tables 1 and 2), were assessed for eligibility and analysed jointly by the researcher and the main supervisor to determine which studies should be excluded. 15 were excluded (Babar et al 2002, Balhara et al (2012), Furnham & Hussain 1999, Gupta et al 2001, Kayano et al 2008, King & Bhugra 1989, Lal & Abraham 2011, Lal & Abraham 2011(Brief report,) McCourt J & Waller 1995, Mammen et al 2007,

Reasons for exclusion were because they were case studies or because they examined possible aetiological factors and psychopathology using comparison between ethnic groups but did not seek to determine the prevalence of eating disorders among South Asian females or because the study participants were not from the South Asian population.

3.3.1 Included studies

Figure 2: Flow diagram of search strategy used to identify and screen relevant epidemiological studies

Total studies identified through database searching (n=471)

Additional studies identified through other sources (n=13)

Remaining studies after duplicates removed (n=247)

Studies excluded with reasons:
- they were clinical/case studies
- they examined prevalence
- participants were not South Asian (n=232)

Studies included in quantitative synthesis (n=13)

Two-stage (n=7)
One-stage (n=6)
Table 5: Studies selected for inclusion in epidemiological review


3.4 Synthesis of extracted data

In the following section, the results are presented in four tables (6,8,9,10); data extracted from the selected studies was tabulated to demonstrate the methodological robustness of each study. The selected studies were critically analysed, highlighting strengths and weaknesses in study design, method and analysis.

3.4.1 Design of included studies

Of the 13 studies; data was extracted in nine categories (See Table 6) : (1) screening tool used, (2) One or two-stage study ( A one-stage study only administers a screening tool and a two-stage study administers a screening tool and also conducts diagnostic interviews with selected participants). (3) Any other measures, (4) sample size, (5) Age range, (6) Ethnicity, (7) Comparator if appropriate, (8) Type of study design, (9) Country. A total of 4,377 participants were recruited to the studies (mean 337).

3.4.2 Study design and setting


3.4.3 Screening

Seven studies used a two-stage design with administration of a screening tool and diagnostic interviews with selected participants (Bhugra et al, 2000, Choudry & Mumford, 1992, Mumford & Whitehouse, 1991 and Mumford et al, 2002 Srinivasan
et al, 1995, Srinivasan et al, 1998) Suhail & Zaib-U-Nisu, 2002). Six were one-stage; these were all carried out in the UK; interestingly six out of the seven, 2-stage studies were carried out in Pakistan or India.


3.4.4 Participants

In 11 studies the participants were all females. Only two studies included both male and female participants (Srinivasan et al, 1995; 1998), though specific numbers of female and male participants were not provided by Srinivasan et al, (1995) or in the follow-up study by the same team on the same participants (Srinivasan et al, 1998).

3.4.5 Age

Participants ranged in age widely (from 9 to 28 years), though this information was not always clearly reported. Four studies provided only a mean range (Dolan et al 1990, Furnham & Adam-Saib 2001, Srinivasan 1998). One indicated the participants as “school girls” (Mumford et al 1991), seven gave a specific age range from nine years being the lowest and 28 the highest (Bhugra et al 2000, Choudry & Mumford 1992, Mumford et al 1992, Button et al 2000, Furnham & Patel 1994, and Hill & Bhatti 1995, Suhail & Zaib-U-Nisa 2002) and two (Ahmed et al, 1994, Srinivasan et al 1995) did not report any information at all about age of participants. No studies explored samples of middle or older aged adults.
3.4.6 Ethnicity

Two studies did not specify or report ethnicity (Bhugra et al, 2000, (n=504 Indian), Mumford et al, 1992, (n=369 Pakistani). Only one study had compared four groups of ethnicity (Furnham & Adam-Saib, 200, (n=38 white), (n=40 Pakistani), (n=44 Bengali), (n=46 Indian). One study compared Indian, Chinese and black Afro-Caribbean participants (Button et al 1998, (n=73 Asian), (n=22 Black), (n=130 Caucasian).

Two studies had Pakistani participants only: (Choudry & Mumford, 1992, (n=271 Pakistani, Suhail & Zaib-U-Nisa 2002, (n=111 Pakistani). Two studies had Indian participants only, Srinivasan et al, 1995, n= 602 also in their follow up study the same team on the same participants Srinivasan et al, 1998.

Four studies compared British Asian and Caucasian: (Ahmed al el 1994, (n=71 Asian) and (n=115 Caucasian) Furnham & Patel 1994, 77.1 % Asian, 22.9 % white from a total of 96; Hill & Bhatti 1995, (n=42 Caucasian) (n=55 Asian); (Mumford et al, 1991, (n=204 Asian and n=355 White).One study compared, Caucasian, Afro-Caribbean and Asian (Dolan et al 1990,(n= 43 Asian), (n=71 Afro Caribbean), (n=365 Caucasian). Even where ethnicity was reported, none of the studies defined ethnicity.

3.4.7 Comparator

## Table 6 Methodology of Included Studies

<table>
<thead>
<tr>
<th>Authors &amp; Year</th>
<th>Screening Tool</th>
<th>1 or 2 stage study</th>
<th>Any other Measures (including diagnostic)</th>
<th>Sample Size</th>
<th>Age Range</th>
<th>Ethnicity</th>
<th>Comparator</th>
<th>Type Of Study (Design)</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bhugra et al (2000)</td>
<td>BITE</td>
<td>2</td>
<td>DSM-III-R *1 Acculturation Questionnaire</td>
<td>504 questionnaires 50 interviews</td>
<td>15-23</td>
<td>Not reported</td>
<td>None</td>
<td>Cross-sectional Questionnaire &amp; Interview</td>
<td>India</td>
</tr>
<tr>
<td>2. Choudry &amp; Mumford (1992)</td>
<td>EAT-26</td>
<td>2</td>
<td>DSM-III-R</td>
<td>271</td>
<td>12-16</td>
<td>Pakistani</td>
<td>None</td>
<td>Cross-sectional Questionnaire &amp; Interview</td>
<td>Pakistan, Mirpur</td>
</tr>
<tr>
<td>5. Srinivasan et al (1995)</td>
<td>EAT-40</td>
<td>2</td>
<td>BITE</td>
<td>602 (Mixed sample male &amp; female)</td>
<td>Not reported</td>
<td>Indian</td>
<td>None</td>
<td>Cross-sectional Questionnaire &amp; Interview</td>
<td>India</td>
</tr>
<tr>
<td>6. Srinivasan et al (1998)</td>
<td>EAT-40</td>
<td>2</td>
<td>BITE -SQ EDS -EDS (Study developed questionnaires)</td>
<td>Data used from 1995 study (Mixed sample male &amp; female)</td>
<td>Mean age 18.2</td>
<td>Indian</td>
<td>Comparison between EDS participants &amp; non cases</td>
<td>Cross-sectional Questionnaire &amp; Interview</td>
<td>India</td>
</tr>
<tr>
<td>No.</td>
<td>Authors</td>
<td>Scale</td>
<td>Stage</td>
<td>Sample Description</td>
<td>Data Description</td>
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<tr>
<td></td>
<td></td>
<td>-BSS</td>
<td></td>
<td>186 total, 71 Asian, 115 Caucasian</td>
<td>Comparison of ethnic groups</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>-PBI</td>
<td></td>
<td></td>
<td>Cross-sectional Questionnaire</td>
<td>UK, Bolton</td>
<td></td>
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<tr>
<td>9.</td>
<td>Button et al (1998)</td>
<td>-EAT-26</td>
<td>1</td>
<td>235</td>
<td>Self categorisation, Caucasian (59.8%) Asian 25.8% (originating for the Indian</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>subcontinent - 25.8% , Black (Afro-Caribbean, 11.0% , Chinese, 3.4% (all of the</td>
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<td></td>
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<td></td>
<td></td>
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<td>total sample)</td>
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<td>Comparison of ethnic groups</td>
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<td></td>
<td>Cross-sectional Questionnaire</td>
<td>UK</td>
<td></td>
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<tr>
<td>10.</td>
<td>Dolan, et al (1990)</td>
<td>-EAT 26</td>
<td>1</td>
<td>Mean age 28.2 yrs</td>
<td>Comparison between the ethnic groups</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>BSQ</td>
<td></td>
<td>365 Caucasian 71 Afro C 43 Asian</td>
<td>Cross-sectional Questionnaire</td>
<td>UK West London</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>11.</td>
<td>Furnham &amp; Adam-Saib (2001)</td>
<td>- Eat-26</td>
<td>1</td>
<td>School girls Mean 15</td>
<td>Comparison between the ethnic groups</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>-PBI</td>
<td></td>
<td>46 Indian 40 Pakistani 44 Bengali 38 White</td>
<td>Cross-sectional Questionnaire</td>
<td>UK</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>-BSS</td>
<td></td>
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<tr>
<td>12.</td>
<td>Furnham A &amp; Patel , R (1994).</td>
<td>-EAT 26</td>
<td>1</td>
<td>British Asian &amp; Caucasian</td>
<td>Comparison between the ethnic groups</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>-BEQ</td>
<td></td>
<td>96</td>
<td>Cross-sectional Questionnaire</td>
<td>UK North London</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Asian 77.1 % White 22.9%</td>
<td></td>
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</tr>
<tr>
<td>13.</td>
<td>Hill, &amp; Bhatti (1995)</td>
<td>- BWH, BE BCS, BSP, DEBQ</td>
<td>1</td>
<td>British Asian &amp; Caucasian</td>
<td>Comparison between the ethnic groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>55 Asian 42 Caucasian</td>
<td>Cross-sectional Questionnaire</td>
<td>UK Birmingham</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>9 year olds</td>
<td></td>
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</tr>
</tbody>
</table>

**Note:**

- DSM-5: Drive for thinness
- BSBS: Body Shape Belief Scale
- BMI: Body Mass Index
- BSQ: Body shape Questionnaire
- FRS: Figure Rating
- BD: Body Dissatisfaction
- BDI: Back Depression Inventory
- EDI: eating disorder inventory
- GFS: Goldfarb fear of fat scale
- EAT-26: Eating Attitude Test
- BWH: Body Weight &Height
- BEQ: Body Esteem questionnaire
- BCS: Body Cathexis Scale
- BSP: Body Shape Preferences
- DEBQ: Dutch Eating Behaviour
- BEQ: Binge Eating Questionnaire
- BITE: Bulimic Inventory Test, Edinburgh
- HADS: Depression Subscale of the hospital Anxiety & Depression Scale
- SQ-EDS: Screening questionnaire syndrome
- EDS: Eating Disorder syndrome
- One-stage study: only administers a screening tool.
- Two-stage study: administers a screening tool and also conducts diagnostic interviews with selected participants.

1* consisting of questions on socio demographic profile with questions on cultural patterns of behaviour, as previously used by El-Islam et al (1985).
2* Based on that developed by Mumford et al (1991).four questions asked about language, dress and food and were scored to provide measures of Western and traditional cultural orientation.
3.5 Prevalence of eating disorders in females: Findings and conclusions of the reviewed studies.

The most common method of assessing for eating disorder prevalence focuses on the prevalence of eating disorder symptoms (such as binge eating, purging and distorted body image), and the profile of symptoms within a particular group (Cummins et al. 2005). Research has documented the relationship between these factors and the development of eating disorders (Stice 1999). In the following section, the prevalence of eating disorders in females and possible associated factors reported by the selected studies will be highlighted; stage-one and stage-two studies will be evaluated separately in order to compare methodologies used. Table 8 summarises the findings and conclusions of the included studies. An inter-rater reliability check was conducted on this and demonstrated 100% agreements between the researcher and an independent PhD student.

3.5.1 Prevalence of eating disorders reported in one-stage studies.

Ahmed et al (1994), reported bulimia attitude scores were significantly higher in Asian participants compared to Caucasians (f=5.35, p=0.025) in the UK. This was partially accounted for by the Asian participants’ greater level of perceived maternal control. Button et al (1998) conducted a study in the UK and found relatively little difference in self-esteem, anxiety, depression, illness perception, eating attitudes and problems according to ethnicity, however self-induced vomiting for weight control was more common among Caucasian females (p<0.01).

Dolan et al (1990) in a UK sample found that Asian participants scored significantly higher on the EAT-26 than Caucasian participants (p<0.05). There was no significant difference between the three groups (Caucasian, British Asian and Afro-Caribbean) on the BSQ. Furnham & Adam-Saib (2001) found that Asian participants scored significantly higher than the white participants on the EAT-26 (p<0.01) in the UK and Body Satisfaction Scale (BSS) was the only significant predictor of EAT scores.
Furnham & Patel (1994) found no significant difference between British Asian and Caucasian participants on EAT-26 scores or significant difference in vomiting. However, Asian girls who felt resentment towards their families had higher EAT scores (significant positive correlation. Hill & Bhatti (1995) found that South Asian and Caucasian nine year olds in Britain placed high priority on thinness. British Asian girls also had significantly higher levels of dietary restraint than Caucasian girls did (t(88)=3.14, p<.01).

### 3.5.2 Prevalence of eating disorders reported in two-stage studies.

Bhugra & Bhui 2000 using the BITE test, reported a low prevalence of bulimia in an all-female college population in North India (0.4%) of 504 participants. None of the participants scored on the DSM-III-R interview as having an eating disorder. Mumford et al (1991) compared rates of eating disorders in South-Asian and Caucasian schoolgirls in Bradford and concluded that adolescent South Asian girls had a higher prevalence of bulimia nervosa (BN) than Caucasians. Out of a sample of 559 high school girls, 3.4% of Asian girls and 0.6% of Caucasian girls were diagnosed as having BN according to DSM-III-R criteria, a statistically significant difference and one Asian participant met the criteria for anorexia nervosa. Choudry & Mumford (1992) carried out a further study in Mirpur, Pakistan using the translated EAT questionnaire and BSQ. Girls scoring above 20 on the EAT-26 were interviewed. One girl met DSM-III-R criteria for bulimia nervosa and none of the girls met the criteria for anorexia nervosa. The Asian girls in the Bradford study had a higher prevalence of bulimia nervosa (3.4%) than females in Mirpur, Pakistan.

Mumford et al (1992) in their Lahore study found one participant met the DSM-III-R criteria for bulimia nervosa, and five met the criteria for partial syndrome bulimia nervosa. No one met the criteria for anorexia nervosa. The mean EAT score (10.1) of girls in Lahore was significantly higher than that of Caucasians in Bradford (7.7). The prevalence of bulimia nervosa among girls in Lahore seemed to be similar to that among Caucasian school girls in Bradford (see table 7 below).
Table 7: Three studies compared on eating disorder diagnosis between Pakistan and Bradford in the between 1991-1992.

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Number of participants</strong></td>
<td>Mirpur N=271</td>
<td>Lahore N=369</td>
<td>Bradford Asian N=204</td>
</tr>
<tr>
<td>Cases of Anorexia Nervosa</td>
<td>0</td>
<td>0</td>
<td>1(0.5)</td>
</tr>
<tr>
<td>DSMIII-R</td>
<td></td>
<td></td>
<td>Bradford Caucasians N= 355</td>
</tr>
<tr>
<td>Cases of Bulimia Nervosa</td>
<td>1 (0.4)</td>
<td>1 (0.3)</td>
<td>7 (3.4)</td>
</tr>
<tr>
<td>DSMIII-R</td>
<td></td>
<td></td>
<td>2 (0.6)</td>
</tr>
<tr>
<td>Cases of Eating Disorder NOS</td>
<td>0</td>
<td>5 (1.4)</td>
<td>2 (1.0)</td>
</tr>
<tr>
<td>DSMIII-R</td>
<td></td>
<td></td>
<td>4 (1.1)</td>
</tr>
</tbody>
</table>

Srinivasan (1995) conducted a study with 662 medical students in India, Madras and found no criteria based diagnosis of anorexia nervosa or bulimia nervosa could be made; 31 of the participants (14.8% of the total examined) were identified as having a syndrome of eating distress (EDS) which did not fit into any of the standard diagnostic criteria for major eating disorders. In his later study Srinivasan (1998) developed a new questionnaire as he recognised that the EAT-40 did not identify individuals with milder form of eating disorders in this population. He called it the Eating Distress Syndrome (SQ-EDS). This 15 item questionnaire was used as a screening questionnaire among the 146 participants, no diagnosis of AN, BN or any partial syndrome of AN or BN was made however sixteen students (11%) were identified as having features of Eating Distress Syndrome (SQ-EDS).

Suhail and U-Nisa (2002) reported prevalence figures of 1.8% and 3.6% for BN and EDNOS respectively in their sample of Pakistani postgraduate women. Results also showed that 50% of the normal weight Pakistani women regarded themselves as overweight. However, there was no correlation between EAT-26 scores and BMI, suggesting that abnormal eating was independent of BMI. They found no cases of anorexia nervosa.
Overall these studies reported a higher prevalence of bulimia than anorexia among Asian females in the UK as well as in the Indian subcontinent. Studies conducted in Pakistan reported similar prevalence rates of diagnosable eating disorders to white British girls (Mumford et al 1991, Mumford et al 1992 & Suhail Zaib-u-Nisu 2002). Studies conducted in India (Srinivasan et al 1995 & Srinivasan 1998) did not find any cases of anorexia or bulimia but identified a syndrome of eating disorders (EDS) which did not fit into the standard diagnostic criteria for major eating disorders. This may simply suggest that Western diagnostic tools may not be appropriate for capturing symptom patterns present among individuals living in non-Western countries, furthermore these tools have not been standardised in the South Asian population and therefore the true level of prevalence rates may be higher than suggested in these studies.

Studies that conducted research in India and Pakistan focused mostly on the prevalence of eating disorders and compared it to the rates in the UK. A very low prevalence of diagnosable eating disorder has been found in Pakistan in comparison to 2.0% to 3.0% that is commonly reported for high school and college populations in more Westernised countries (Hsu, 1996). For example Choudry & Mumford 1992, found no cases of Anorexia Nervosa and only one case of BN (0.4%) by DSM-III-R criteria in a sample of 271 schoolgirls.

All Studies of eating disorder symptoms that used the EAT-26 as a screening test, suggested that “abnormal eating patterns” may exist in 7.0-29.0% of adolescents and young adults in India and Pakistan (Choudry & Mumford, 1992). Choudry & Mumford (1992) stated that the Eat-26 might not have been a culturally valid measure for use for these groups of females. Furthermore the use of DSM diagnostic criteria with non-Western populations may be problematic, for example, researchers suggest using different diagnostic criteria for Indian girls, rather than the Western population, as “fear of fatness” is not evident in Indian girls (Sjostedt et al , 1998; Tareen, Hodes, & Rangel, 2005) or excessive dissatisfaction with the weight and shape of the abdomen, hips and thighs (Mumford et al 1991) which are typically
encountered in eating disorders (DSM IV; American Psychiatric Association, 1994). However others argue urban communities in India have started to aspire to new body ideals and the concept of ‘slim is beautiful’ (Gandhi, Appaya, & Machado, 1991).

It has been argued that the use of Western diagnostic criteria within non-Western populations has contributed to misleading findings (King, 1993; Wildes, Emery, & Simons 2001). Wildes et al (2001) goes further and argues that research with ethnic minority groups in Western countries has indicated that ethnic and cultural variables are more significant in influencing sub-threshold eating disorders than clinical pathology.

Although these one-stage studies reported that Asian participants scored significantly higher than Caucasian participants on the screening tools, they were unable to report whether participants had a diagnosable eating disorder as they were not clinically interviewed. The screening tools used to assess eating attitudes have been scrutinised when conducting research within the Asian population. High scores could be due to the inaccurate interpretation of the questions and lower levels of English proficiency rather than actual differences in eating attitudes. Furthermore, the scoring of tests is usually based on Western norms, which may skew the interpretation of the data (King & Bhugra, 1989). Also, they may not reflect the eating disorder symptomology that is typically present among people in Asian countries (Makino, Tsuboi, & Dennerson, 2004). Factors such as language, literacy, and ethnicity have been shown to have an effect (Escobar et al, 1986; Tombaugh and McIntyre, 1992) on understanding and interpreting the questions.

3.6 Etiological factors

Aetiology of eating disorders is complex. Traditionally studies have focused on Western based values, such as the pressure to be thin and the internalization of body ideals that may put individuals at risk for this condition (Stice, 2001). However, research that involves diverse populations may need to consider many other
sociocultural factors that make up the aetiology of eating disorders. In the section below etiological factors identified by the selected studies will be highlighted.

3.6.1 One-stage studies

Ahmed et al (1994) found higher paternal control in Asian participants scores partially explained the difference between Asian and Caucasian BSS scores with Asian girls being more satisfied with their bodies than Caucasian participants (f=4.29, p=0.04). Button et al (1998) found that for participants living with a parent or partner, vomiting was significantly associated with living status (x²=12.6, df=3, p=.005), with those living with partner or parents five times more likely to have made themselves sick for weight control (16.4% of those not living with partner/parents and 3.2% of those who lived with partner/parents). They suggested that the low rate of referral of Asian women to eating services cannot be accounted for simply by different health-seeking behaviour on their part. Furthermore, it was suggested that this raised the possibility that they are either presenting in a different way from Caucasian women and/or that there is some difference in GP perception/behaviour. Dolan (1990) argued that although EAT scores were significantly higher (p<0.05) among Asian participants compared to Caucasian participants, disordered eating was positively correlated with anxiety and depression among the Caucasian group only. The study did not record possible associated factors relating to the high EAT scores of Asian participants.

Furnham & Adam-Saib (2001) concluded that although significant differences were found between the four ethnic groups (White, Indian, Pakistani and Bengali) the Parental Bonding Instrument (PBI) over-protection score was not associated with EAT-26 and BSS scores across all groups. Furnham & Patel (1994) found British Asian females who felt resentment towards their families had higher EAT scores. Resentment was measured using a questionnaire devised specifically for this study, concerning the perceived level of integration into British society. Results from this
measure should be treated with caution as this measure has not previously been validated.

Hill & Bhatti (1995) found that British Asian girls reported significantly higher levels of dietary restraint than Caucasian girls did and this was marginally correlated with a more traditional cultural orientation, \( t(26)=2.04, p = .05 \), this was measured using a short assessment of cultural orientation based on that developed by Mumford et al (1991).

These studies suggest a strong association between parental control and the development of eating disorders among the UK Asian participants. However as these findings are based on questionnaires alone and no clinical interviews took place so the extent of family conflict cannot be determined. In light of these findings, a qualitative study (Study 3) was conducted in order to explore the issues around family and service provision for South Asian females with eating disorders. This is presented in Section 3.

3.6.2 Two-stage studies

Bhugra & Bhui (2000) found that ‘sociocentrism’ (defined as being orientated toward society and taking one’s own social group as the standard against which others are measured) and impulsivity accounted for a significant amount of variance (43.8%) in the BITE score. They found no effect of age, social class, religion or height on the distribution of BITE scores and also acculturation was not related to BITE scores. They also found that virtually all interviewees had sociocentric views of themselves measured by the acculturation questionnaire previously used by El-Islam et al (1985). They concluded that the role of family/social level values coincided with the individual’s values, accounting for the low rates of bulimia, with respondents seeing their identity primarily linked with being part of their family. They saw themselves as being defined by their personal relationships (friends and family) and found it difficult to defining themselves outside of these.
Mumford et al (1991) found that, among the Asian participants in their study, high EAT and BSQ scores were associated with a more traditional cultural orientation and not with greater Westernization. Mumford et al (1991) and Choudry & Mumford (1992), in trying to account for differences between Bradford and Mirpur, argued that, it may be likely that the Asian girls in Bradford were suffering the effects of growing up in a Western culture. They commented how Asian parents in Bradford feel threatened by Western culture and are overprotective; they are compelled to send their daughters to school but are not enthusiastic about further education. By contrast, Mirpuri parents encourage their daughters to obtain good academic results. Furthermore, they argued this difference seemed to be associated with greater intra-familial conflict and higher levels of stress and anxiety among Asian girls in Bradford than the girls in Mirpur. The reasons behind the prevalence of eating disorders among these groups of females are considered important in order to understand the development and maintenance of the disorder, thus there is a need to carry out a review of qualitative studies which will be discussed in Section 2, Chapter 3.

Srinivasan et al (1995) argued that a significant number of Indian female participants had conflicts with regard to their eating habits and body shape and were at possible risk for developing more serious disorders. Furthermore, they argued as the social pressure to be slim increases in India, eating disorders will increasingly emerge there in the future. Srinivasan et al (1998) argued that in the past few years in India, there have been changes in culture, the Western concepts of beauty and slimness is diffusing among the youth; this is predominantly occurring in urban areas and economically advanced societies, especially through the mass media.

Suhail & Zaib-U-Nisu (2002) found that participants were dieting because they were worried about marriage prospects, and stated that in Pakistani culture, a girl must be married at an ‘appropriate’ age otherwise it causes emotional, if not economic, strain on the whole family. Furthermore, they argued that faulty eating patterns in these women were not induced by their real weight, but by their psychological feeling of
being fat and dissatisfaction with their body shape, which may induce depressive symptoms.

These results demonstrate the appeal for thinness among South Asian females, which in combination with inter-cultural and inter-familial conflict, may strongly influence eating behaviour and contribute to the development of eating disorders. Eating disorders may be one result of a culture clash that occurs because of intra-familial factors that stem from control issues as the young females tries to accept demands of two different cultures that are not consistent with one another (Bryant-Waugh&Lask, 1991).
### Table 8 RESULTS- findings/prevalence & Conclusions of included studies

<table>
<thead>
<tr>
<th>Two stage studies</th>
<th>Findings / prevalence</th>
<th>Conclusion</th>
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<tbody>
<tr>
<td><strong>Bhugra &amp; Bhui 2000</strong></td>
<td>Low prevalence of bulimia -0.4% of 504 participants. Sociocentrism and impulsivity account for a significant amount of the variance (43.8%) in BITE score.</td>
<td>There was no effect of age, social class, religion or height on the distribution of BITE scores. Three key factors emerged; 1) impulsivity/sociocentric avoidance, 2) associated attitudinal responses 3) depressive thinking with features of helplessness and feeling of failure.</td>
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<tr>
<td>Questionnaires</td>
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<tr>
<td>Interviews</td>
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<tr>
<td></td>
<td>No one scored on the DSM-111-R interview as having an eating disorder.</td>
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<tr>
<td></td>
<td>The role of family/social level values coincide with the individual’s values, accounting for the low rates of bulimia49/50 respondents saw their identity linked with being part of their family. They also saw themselves as being defined by their personal relationships (friends and family) and found it difficult to defining themselves outside of these.</td>
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<tr>
<td><strong>Choudry &amp; Mumford (1992) Mirpur</strong></td>
<td>A survey of eating disorders was conducted in Mirpur, Pakistan using Urdu translated EAT questionnaire.</td>
<td>Suggest the EAT-26 can be successfully translated into Urdu. 1 case of Bulimia was identified in the present sample using this measure.</td>
</tr>
<tr>
<td>Questionnaire</td>
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<tr>
<td>Interview</td>
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<tr>
<td></td>
<td>Translation of the EAT-26 into Urdu – several items were altered to have milder wording, No significant difference was found between the English and Urdu EAT-26 measures (paired t-test=.27, NS).</td>
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<td>Girls who scored highly on either questionnaire were interviewed Out of 271 participants, 19 (7%) scored above 20 on the EAT-26. Out of these 12 conducted interviews, none of which met criteria for anorexia, 1 met the criteria for bulimia (EAT score = 37).</td>
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<tr>
<td><strong>Mumford et al (1991)</strong></td>
<td>Among the Asian females, high EAT and BSQ scores were associated with a more traditional cultural orientation and not with greater westernisation.</td>
<td>Factor analyses of the EAT and BSQ supported their cross-cultural conceptual equivalence in this South-Asian population. Among the Asians, high EAT and BSQ scores were associated with a more traditional cultural orientation and not with greater Westernization.</td>
</tr>
<tr>
<td>Questionnaires</td>
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<tr>
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<td>In both ethnic groups, there was correlation between EAT and the BSQ (Spearman’s rho: Asians 0.57, Caucasians 0.51). The BSQ correlated with the BMI in both groups (Asians 0.39, Caucasians 0.40). The EAT correlated poorly with the BMI in the Caucasian girls (0.13, P&lt;0.05); with the Asians, there was no significant correlation.</td>
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</table>
**Interviews**

At Interview, seven Asian girls and two Caucasian girls met the DSM-III-R criteria for bulimia – a prevalence of 3.4% and 0.6% respectively (Fisher’s exact test- this was a significant difference, P<0.05). One Asian girl met DSM-III-R criteria for anorexia nervosa.

**Mumford et al (1992) Lahore Questionnaire**

Factor analysis of the EAT and BSQ supported their cross-cultural validity. The girls with the highest “Westernised” scores had the highest EAT and BSQ scores. The mean EAT score of the participants in the present study was higher than that in the comparison study (UK participants) [t(722)=4.036, p<.001].

1 participant met DSM-111-R criteria for bulimia nervosa, 5 girls met criteria for partial syndrome bulimia nervosa. No girls suffered from anorexia nervosa.

**Interview**

Eating disorders do occur in English-medium schools in Lahore. But the author states that it is possible that the optimal cut-off for the EAT-26 is lower for this population, and that they failed to interview some girls with eating disorders who scored below the threshold.

Prevalence of bulimia nervosa is similar to the Caucasian schoolgirls in Bradford.

**Srinivasan (1995) Questionnaire**

Among the 210 participants (mixed male and female) assessed individually, no criteria based diagnosis of anorexia nervosa or bulimia nervosa could be made, 31 of participants (14.8% of the total examined) were identified as having a syndrome of eating distress (EDS) which did not fit into any of the standard diagnostic criteria for major eating disorders.

The authors state that the relationship between EDS to anorexia nervosa and bulimia nervosa can only be understood by future observations on this population.

**Interview**

The authors state that it is probable that eating disorders manifested in the form of EDS rather than as anorexia nervosa and Bulimia because of the absence predisposing personal history and family variables and due to protective effect of cultural norms and attitudes.

**Srinivasan (1998) Questionnaire**

6 participants were identified as having features of EDS (the validity of this questionnaire needs further testing).

Among the 146 participants no diagnosis of AN, BN or any Partial syndrome of AN or BN was made.

**Interview**

The author states that restrained eating and faulty eating patterns in women are not induced by their real weight, but by their psychological feeling of being fat and dissatisfaction with their body shape, which may induce depressive symptoms.

**Sohail & Zaib-U-Nisa (2000) Questionnaire**

Nineteen participants (17%) scored above the EAT-26 threshold and 20 participants (18%) scored above the BSQ threshold. Only 14 participants scored above these thresholds on both questionnaires.

Two multiple regression analysis were computed to find the best predictors of disturbed eating attitudes and depressive symptoms. The analysis with the EAT-
| Interviews | 26 used as a dependent variable, when all the variables were entered in the equation, both high Media Exposure (ME) and concerns about body shape were the best predictors of abnormal eating attitudes and behaviour (R=0.63; R² =0.40). Dissatisfaction with weight (DW), depressive affect and BMI had no significant variation in eating attitude scores. 

The second regression analysis with depression as dependent variable, indicated that the scores on BSQ were the best predictor of depressive symptoms (R=0.48; R²=0.23). Two participants met the DSM-IV diagnostic criteria for BN another two were diagnosed as EDNOS giving a prevalence of 1.8% for bulimia and 3.60 for all eating disorders. During the diagnostic interviews, three women admitted they were worried about their marriage prospects. |
|---|---|
| One-Stage studies | Ahmed et al (1994) Questionnaire | Bulimia attitude scores were significantly higher in Asian participants compared to Caucasians (f=5.35, p=0.025). Maternal and paternal overprotection scores were also significantly higher in Asian participants compared to Caucasians (f=20.3, p=0.001; f=5.96, p=0.02, respectively). 

Dissatisfaction with bodies (BSS) was greater in participants who saw their parents as more controlling (PBI) [Spearman’s rho = .25, p<0.01 for correlations between maternal and paternal overprotection scores, and BSS scores]. 

Higher EAT-26 and BSS scores (also known as eating pathology) was associated with low maternal care and high paternal control (see Table 2 for correlations). Asian participants’ bulimic attitudes scores correlated with higher levels of maternal control (Spearman’s rho = 0.24, p<.025). Further, maternal control partially accounted for the difference between Asian and Caucasian participants’ bulimia attitude scores (f=4.46, p=0.04). 

Higher paternal control in Asian participants scores partially explained the | Asian participants had greater levels of bulimic attitudes then Caucasian participants. This was partially accounted for by Asian participants’ greater levels of perceived maternal control. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Button, Reveley &amp; Palmer (1998)</td>
<td>Difference between Asian and Caucasian BSS scores with Asian girls being more satisfied with their bodies than Caucasian participants ($f=4.29, p=0.04$).</td>
</tr>
<tr>
<td>Questionnaires</td>
<td>Relatively little difference in eating attitudes and problems according to ethnicity, but self-induced vomiting for weight control was more common among Caucasian women ($p&lt;0.01$). Vomiting was significantly associated with living status ($x^2=12.6, df=3, p=0.005$), with those living with partner or parents five times more likely to have made themselves sick for weight control (16.4% of those not living with partner/parents).</td>
</tr>
<tr>
<td>Dolan, B. Lacey H, J &amp; Evens, C (1990)</td>
<td>Asian participants scored significantly higher on the EAT-26 than Caucasian participants (ANOVA: $f$ ratio=3.02, $f$ probability=0.049; Duncan’s range test: $p&lt;0.05$). There was no significant difference between the three groups (Caucasian, British Asian and Afro-Caribbean) on the BSQ.</td>
</tr>
<tr>
<td>Questionnaires</td>
<td>In the Caucasian group only, disordered eating was positively correlated with anxiety and depression.</td>
</tr>
<tr>
<td>Furnham &amp; Adam-Saib 2001</td>
<td>Asian participants scores were significantly higher than the white scores on the EAT-26 ($f=7.53, p&lt;0.01$) and PBI, but not the BSS (Body Satisfaction Scale). The Bangali sample had significantly higher EAT-26 total ($f (3.164)=16.65, P&lt;0.01$) compared to Pakistani and Indian groups and the white British groups. Out of the three factors the ‘oral control’ scores revealed a significant result $F (1,166) = 11.02, P &lt; 0.01$, with British-Asians scoring significantly higher than the White group. BSS score was the only significant predictor of EAT scores.</td>
</tr>
<tr>
<td></td>
<td>That there are important psychological differences between second-generation migrants from different countries on the Indian subcontinent.</td>
</tr>
<tr>
<td>Hill &amp; Bhatti (1995)</td>
<td>Dietary restraint was higher in Asian participants than Caucasian participants ($t(88)=2.39, p&lt;.05$). No other group differences. Highly restrained girls were significantly older and weighted more than low restrained girls (smallest $f(1,46)=4.38, p&lt;.05$). Highly restrained girls were significantly more dissatisfied with their weight ($f(1,46)=6.99, p&lt;.05$). There were significant main effects of restraint on choice of current shape and overall body shape satisfaction ($f(1,46)=4.16, p&lt;.05$; $f(1,46)=12.62, p&lt;.01$ respectively).</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>The study confirms the presence of body dissatisfaction and reported dieting in nine year old girls. Asian and British girls both displayed a priority for thinness. Restraint was associated with many of the factors associated with eating patterns. These results demonstrate the wide appeal for thinness, which in combination with intercultural and interfamilial conflict, may strongly influence eating and contribute to the development of eating disorders.</td>
</tr>
<tr>
<td>Furnham &amp; Patel</td>
<td>No significant difference between British and Asian participant EAT-26 scores.</td>
</tr>
<tr>
<td></td>
<td>British and Asian groups did not differ in terms of EAT scores. No</td>
</tr>
<tr>
<td>(1994), Questionnaires</td>
<td>No correlation between age and EAT scores ($r=.05$, NS). No significant difference in EAT score between high and low socioeconomic groups. 2 of 5 resentment items showed that Asian girls who felt resentment towards their families had higher EAT scores (significant positive correlation). However, one resentment item showed a significant negative correlation. No evidence to support that Asian girls who integrated into society had higher EAT scores compared to those that did not integrate. No significant difference in vomiting was found between Asian and British participants.</td>
</tr>
</tbody>
</table>
3.7 Quality assessment of included studies

Methods used by each of the selected studies raised methodological problems which were highlighted through an initial quality assessment (see table 9) and a ‘cultural quality assessment’ (studies were rated as high or low quality, see table 10).

3.7.1 Research question or hypothesis/ specific objectives

All the studies aimed to estimate prevalence of eating disorders or abnormal attitudes to eating. Several also, as indicated above, aimed to explore associated cultural and ethnic differences and how these might be aetiologically related to the prevalence of eating disorders for Asian females.

Mumford et al (1991) in their Bradford study, hypothesised that there would be significant differences between the Asian and Caucasian EAT and BSQ scores and that eating disorders would only be found amongst the most ‘Westernised’ of the Asian girls. Choudry and Mumford’s (1992) Mirpur study was conducted to translate and validate the EAT-26 into Urdu by conducting a survey in an Urdu medium school in Mirpur. Since most of the Pakistani families who settled in Bradford came from rural Azad Kashmir (Mirpur District), this survey was also conducted to allow a more direct comparison with the Bradford data. Mumford et al (1992) Lahore study aimed to assess the validity of the Eat-26 and BSQ when used in English with school girls in Lahore and to identify the social and cultural factors which correlated with both high scores on questionnaires to assess attitudes to eating and diagnosed eating disorders.

Srinivasan et al, (1995), aimed to study the nature and prevalence of eating disorders in a native Indian student population. In their other study, Srinivasan et al, (1998) stated two main aims: firstly to develop a screening instrument applicable to populations who exhibit other milder forms of Eating Disorders, secondly, to examine the phenomena of Eating Distress Syndrome (EDS) and study the variables


3.7.2 Where was the target population recruited from?

Most studies (n=11) recruited participants from schools and colleges but one (Button et al 1998) study selected from a single medical practice in Leicester and one (Dolan et al 1990) from a family planning and well women clinic in London. These studies cannot generalise the results since the participants were mostly from one particular type of setting.

3.7.3 How were the target population selected?

Studies conducted in the UK concentrated on locations densely populated with South Asian. Nearly all of them recruited school age (14-16 year old) girls from the classrooms. Studies conducted in the subcontinent recruited participants from college or university and therefore older participants than their UK counterparts.

3.7.4 How was the target population recruited?

Nearly all the studies recruited through the teaching staff at the school or college and questionnaires were distributed in class. Button et al (1998) recruited through computerized records in primary care. A target population of 486 was identified and sent questionnaires and letters from the GP. Dolan, et al (1990) recruited from a waiting room of a family planning clinic.
3.7.5 Sample size calculation

None of the studies recorded a sample size calculation, which is crucial to quantitative research which seeks to make generalizations from the study results to the wider world. To generalize in this way, it is essential that sample size is appropriate, so that the results are shown to be representative, and that the statistics can discern associations or differences within the results of a study (Fox et al 2000).

3.7.6 Were participants debriefed?

Only one study (Furnham & Adam-Saib 2001) debriefed participants at the end of the study to discuss their findings. Debriefing participants is an important way of ensuring that participants were happy with taking part and given an opportunity to ask questions about the findings but importantly, it also gives the researcher an opportunity to ask the participant about their experience of taking part and about the procedure itself. For example, did the participants find the questionnaires easy to complete, how can they be improved? This can help the researcher to improve on their research methods for future studies. Debriefing is important and not solely for the purpose of ethical duty. It has importance as a tool for positive participant-research relations, participant feedback and an opportunity for education (Malamuth & Check 1984).

3.7.7 Generalisation of the study results

One study (Furnham & Adam-Saib 2001) did not record the potential for generalizability or otherwise of their study results; the other studies clearly stated that their samples were not representative of the general population as they conducted their research within one geographical area and population so therefore, the results could not be generalized. Overall sampling and recruitment led to the possibility of selection bias and skewed findings as these studies recruited from educational institutions, one geographical area and high socio-economic status.
(South Asian subcontinent). This limits the generalizability of the findings to the adult South-Asian population and individuals from low economic status. It may also underestimate the prevalence of eating disorders in this population and therefore future research needs to be carried out among the under-represented groups.
Table 9: Quality assessment of included studies.

<table>
<thead>
<tr>
<th>Author</th>
<th>Research question or hypothesis/ specific objectives</th>
<th>Where was the target Population recruited from</th>
<th>How were the target population selected</th>
<th>How was the target population recruited</th>
<th>Sample size calculation</th>
<th>Were participants debriefed</th>
<th>Generalisation of the study results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bhugra &amp; Bhui (2000)</td>
<td>1. Wanted to estimate the prevalence of bulimic disorders in a group of female college students. 2. Investigate the relationship between sociocentrism and eating disorders.</td>
<td>Private all girls colleges in Industrial town in north India</td>
<td>A district town with several institutions for higher education, randomly choose classes on four different days</td>
<td>Through the teaching staff at the college. Questionnaires distributed in class and collected in the same period. Questionnaires chosen randomly on a one in ten basis for an interview</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>‘As there were no refusals in filling in the questionnaire or interviews, the sample can be seen as typical and representative of a middle-class student population.’ Bhugra &amp; Bhui (2000). Limitations of no control group acknowledged.</td>
</tr>
<tr>
<td>Choudry &amp; Mumford (1992)</td>
<td>1. To translate and validate the EAT in Urdu. 2. To conduct an eating disorder survey in an Urdu medium school in Mirpur.</td>
<td>Female medical students at Fatima Jinnah Medical College and Kinnaird College for Women, Lahore, Pakistan.</td>
<td>Because of the close links with Pakistani communities in Britain, school girls in Mirpur are more likely what The catchment area of schools include Mirpur town, surrounding villages and countryside. Girls aged 14-16</td>
<td>Through headmistress at the college, high scorers on EAT interviewed</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Author argues Mirpur is in some respects unusual and we must exercise caution in generalizing results to other provisional towns or rural areas of Pakistan</td>
</tr>
<tr>
<td>Mumford, et al (1991)</td>
<td>Hypothesised that there would be major discrepancies between Asian and Caucasian girls in their pattern</td>
<td>Secondary School girls of Bradford. Four state schools in the Bradford area, 4th and 5th yr secondary school girls aged 14 to 16 yrs</td>
<td>School via teachers. High scores on EAT or BSQ Interviewed</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Without adequate baseline data, we can only speculate that the high prevalence of bulimia nervosa</td>
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</tbody>
</table>
of EAT and BSQ responses, giving instruments limited cross-sectional validity; that the prevalence of eating disorders would be much lower among the Asian girls; and that eating disorders would only be found among the most 'Westernised' of the Asian girls.

Mumford et al (1992)

| 1. Assess validity of EAT-26 & BSQ in English with schoolgirls in Lahore. | 3 English medium girls schools in Lahore, Pakistan | Lahore was chosen for ease of surveying English medium schools, which serve a wealthy population of upper social class. Girls aged 14-16 | Via teaching staff at the schools plus letters sent to parents about the study. High score on Eat/BSQ interviewed. | Not recorded | Not recorded | The prevalence of bulimia nervosa seems to be similar to that among Caucasian school girls in Bradford. |


| The aim to study the nature and prevalence of eating disorders in a native Indian student population. | Sri Ramchandra Medical College and Research Institute – Madras | Not recorded | Not recorded | Not recorded | Not Recorded | Not Recorded |


| Two main aims: 1. To develop a screening instrument | Medical college In Madras | Not recorded | Not recorded | Not recorded | Not Recorded | Not Recorded |
applicable to populations who exhibit other milder forms of ED

2. To examine the phenomena of Eating Distress Syndrome (EDS) and study the variables associated with it.

<table>
<thead>
<tr>
<th>Study</th>
<th>Objective</th>
<th>Setting</th>
<th>Participants</th>
<th>Methodology</th>
<th>Sample Size</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suhail &amp; Zaib-U-Nisa (200)</td>
<td>To assess the prevalence of disturbed eating attitudes in postgraduate female students in Lahore, Pakistan</td>
<td>Punjab University and government college Lahore</td>
<td>The departments of both institutes (Punjab University and government college have comparatively greater number of female students)</td>
<td>Students were contacted (not said how) those who agreed to participate were asked to complete questionnaires.</td>
<td>Not recorded</td>
<td>Authors argued that participants were from higher middle to upper classes which limits the validity of the findings</td>
</tr>
<tr>
<td>Ahmed et al (1994)</td>
<td>1. Asian (Indian Subcontinent) school girls will rate their parents as over controlling than their Caucasian peers. 2. The Asian schoolgirls will have more unhealthy eating attitudes than their Caucasian peers.</td>
<td>Bolton, 4th year mixed sex state comprehensive</td>
<td>4th year</td>
<td>By the teachers in class. Not stated how recruited</td>
<td>Not recorded</td>
<td>This research needs to be extended to other groups before the reality or the generalizability of reducing perceived parental protectiveness might reduce the conflict over control, can be determined.</td>
</tr>
<tr>
<td>Button et al (1998)</td>
<td>Objective: to investigate possible differences in eating</td>
<td>One practice in Leicester, UK</td>
<td>Women aged 18 to 27 yrs</td>
<td>Through computerized record a target population of</td>
<td>Not recorded</td>
<td>²The large proportion of Sikh women in our</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Study Description</td>
<td></td>
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</tr>
<tr>
<td>Dolan, et al (1990)</td>
<td>Measure and compare eating attitudes and behaviour as well as feelings about weight and shape in three ethnic groups. South west London, at a family planning and well-women clinic. Used the 1991 Census data to identify areas of Leicester with a high population from an Asian background. Waiting room of the clinic. Not recorded Not recorded Sample not representative of the general population, therefore cannot generalize results.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Furnham &amp; Adam-Saib (2001)</td>
<td>Examine attitudes to eating and body satisfaction in 2nd generation Indian, Pakistani, Bengali and White teenage girls in Britain and to investigate the relationships between these attitudes and parental control. Two secondary schools and a youth group in London. All women attending the clinic were asked by the first author if they would take part in the study. Once appropriate permission was obtained, questionnaires were administered by the second author to students who agreed to participate. Not recorded yes Not recorded</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Furnham &amp; Patel (1994).</td>
<td>To examine dietary, weight and eating attitudes of 12-18 year old British Asian. A mixed sex, middle-class state run school in North London. Once agreed to take part given a booklet to complete in their own time and. Over a four week period a teacher and her colleague administered the. Not recorded Not recorded The sample in this study was not particularly large nor heterogeneous.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Hill, &amp; Bhatti (1995).</td>
<td>How pre-adolescent girls view their weight and body shape?</td>
<td>Three state middle schools, mixed sex and located in the inner city region of a northern British city.</td>
<td>All the girls attending the school on the study day were included in the analysis</td>
<td>Through the schools</td>
<td>Not recorded</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>
3.8 Cultural sensitivity of included studies

For each of the included studies the cultural sensitivity applied in methodology was assessed (see table 10).

3.8.1 Was the ethnicity of the target population defined?

Two studies (Dolan et al 1990, Furnham & Patel 1994) judged ethnicity by the birth place of the subject. Three studies (the Ahmed et al 1994, Bhugra et al 2000, Mumford et al 1991,) did not define ethnicity. Two studies (Button et al 1998, Furnham & Adam-Sahib 2001) defined ethnicity as “those from the Indian subcontinent”; one (Hill & Bhatti 1995) defined ethnicity from self-recording by the participant; one (Choudry & Mumford 1992) as Mirpuris and one (Mumford et al 1992) as Pakistani. There needs to be consistency across cultural research into the way in which ethnicity is defined as it is important to be able to understand and examine sociocultural factors in aetiology across ethnic groups.

3.8.2 Special consideration in selecting measuring tool

One study (Bhugra et al 2000) modified the BITE questionnaire for the purpose of their study. Questions on socio-demographic profile were added along with questions on cultural patterns of behaviour, as previously used by El-Islam et al. (1985). These questions covered cultural behaviours, such as degree of comfort in the culture, languages spoken, preferences for certain foods and entertainment as well as dress. One study (Mumford et al 1991) added four questions to measure “Western” and “traditional” cultural orientation, and two other studies (Mumford et al 1992, Hill & Bhatti 1995) also used these questions. One study (Button et al 1998) included three vignettes designed to assess illness perception and health seeking behaviour. One study (Furnham & Patel 1994) devised a questionnaire to investigate the level of integration of Asians into British society.
3.8.3 Language offered

Hindi and English (Bhugra et al 2000) were offered to Indian participants in India. Dolan et al (1990) did not include participants in his UK study if they could not read English; Mumford et al 1992, offered English only to Urdu speaking participants in Pakistan as it was thought the standard of English was very high as the participants were from a wealthy upper social class, therefore Urdu was not required. Choudry & Mumford (1992) made Urdu as a language provisions for their Mirpur participants in Pakistan. Studies which conducted research in the UK only offered English. It is important the participants of ethnic origin are offered language of their choice as they need to understand and feel comfortable about what they want to contribute to the research.

3.8.4 Language Opted - Ethnic/English

Bhugra et al (2000) was the only study that offered two languages, but the study did not record which language the participants opted for.

3.8.5 Process of translation

Six studies (Bhugra et al 2000, Choudry & Mumford 1992, Mumford et al 1992, Srinivasan el al, 1995, Srinivasan et al, 1998, Suhail & Zaib-U-Nisu 2002) conducted research in the subcontinent. In Bhugra et al’s (2000) study bilingual psychiatrists translated the BITE questionnaire into Hindi and it was then back translated by bilingual graduates from the same culture and society. Choudry & Mumford (1992) set up a translation committee, which translated the EAT-26 into Urdu, back translated and rephrased some of the items to the need of the Mirpur participants. Two studies (Mumford et al 1992, Suhail & Zaib-U-Nisu 2002) did not translate any of the questionnaires. Mumford et al 1992 argued that, as the standard of English in schools of Lahore was very high they had no difficulties in administering the questionnaire.
During Srinivasan et al’s (1995) study it was recognised that the screening tools were not standardised for the Indian population and the prevalence of severe eating disorders was low. They therefore, designed the SQ-EDS questionnaire which was administered in their later study (Srinivasan et al 1998). However this was not translated into the participants' first language.

It is important to develop and implement, where appropriate, culturally sensitive tools for South Asian females to enable researchers to understand factors important in the development of eating disorders; but most importantly, the participant is able to understand and relate to the questions being asked, which will produce more reliable data.

**3.8.6 Ethnic matching of interviewers**

Only Bhugra et al’s (2000) study mentioned that the first author who administered the interview had the same ethnic matching as the participants. This can be seen as important to allow the participants to feel comfortable about asking questions and being able to relate to the researcher in terms of culture and ethnicity. This matching appears to be important because it is believed that the quality of the data will be improved because matched interviewers have a greater potential to understand and empathise with respondents’ circumstances, culture and experiences than non-matched interviewers (Elam & Fenton, 2003).

**3.8.7 Cultural consideration in interviewer/interpreter training**

None of the studies mentioned cultural consideration in interviewer/interpreter training. Such training is considered to be an important aspect of working with all ethnic minority participants as it allows the researcher to understand some aspects of the culture.
3.8.8 Was the family consulted?

Only one study (Mumford et al 1992) mentioned consulting with the participant’s family by letter for their consent. It is important to consult or inform family members about any research that is taking place where potential participants are under 18 years as this will allow the researcher to put the family members at ease and also understand some of their issues and concerns. This may also limit inclusion and bias findings as possible participants may feel that parents will be informed about their involvement; but reassuring about confidentiality may help overcome this.

3.8.9Were community agencies consulted?

None of the studies mentioned consulting with community agencies. Consultation would have enabled the researcher to gain information about what services these agencies offer and what are the main issues that South Asian women are faced with. It would also be an opportunity to recruit potential participants. Literature on the value of public and patient involvement in research is good practice, for example Crowford et al (2002) carried out a systematic review involving patients in the planning and development of health care and found that evidence to support involvement of patients contributing to changes in the provision of services across a range of different settings.

3.8.10 Were interpreters used?

In order to allow participants whose first language is not English to fully express themselves, consideration should be given to the use of an interpreter to manage the communicative exchange between the researcher and participants. None of the studies mentioned the use of interpreters. There is a general consensus among researchers interested in cross-cultural communication that the lack of common language between the professional and participant/patient is an obstacle to adequate
service delivery (Taylor et al 2013). Using professional interpreters, who are formally trained to interpret for clients and professionals, is widely considered to be an appropriate way of overcoming the language barrier in such consultations (MacFarlane et al, 2009; Bischoff et al, 2003; Horberger et al, 1996).

3.8.11 Was validity and reliability of translated questionnaires tested?

Choudry & Mumford (1992) used a cross-over design to ensure that any systematic test-retest discrepancies were cancelled out. Significant discrepancies were modified. Mumford et al (1991) developed and validated their acculturation scale by carrying out a pilot study. None of the other studies reported doing this.

In order to conduct cross-cultural studies, measurement tools need to be adapted to use in both cultures (Guillemin et al 1993), especially when emotional or sensitive topics are involved, which can result in improvised accounts (Nicassio et al, 1986; Westermeyer, 1990) as well as making the grounded accuracy and value of the data uncertain (Marshall & Whille, 19994). For example, King & Bhugra (1989) found that 29% of Indian schoolgirls scored above the recommended threshold for the EAT-26. However on closer analysis of the responses showed that linguistic and cultural factors were important, as several questions were liable to misinterpretation for cultural and religious reasons.
<table>
<thead>
<tr>
<th>Author</th>
<th>Any South Asian authors</th>
<th>Were the target population ethnicity defined?</th>
<th>Special consideration in selecting measuring tool</th>
<th>Language offered</th>
<th>Language opted Ethnic/ English</th>
<th>Process of translation</th>
<th>Ethnic matching of interviewers</th>
<th>Cultural consideration in interviewer/ interpreter training</th>
<th>Consultation with family</th>
<th>Consultation with community agencies?</th>
<th>Were interpreters used</th>
<th>Were validity and reliability of translated questionnaires tested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bhugra, et al (2000)</td>
<td></td>
<td>No definition of the participants ethnicity, but religion in demographic data</td>
<td>The BITE was modified by the authors for the purpose of their study</td>
<td>Hindi, English</td>
<td>Not recorded</td>
<td>Bilingual psychiatrists translated BITE into Hindi, translated back by bilingual graduates from the same culture and society</td>
<td>First author administered interview</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>No</td>
<td>Did not mention the reliability / validity of the translated questionnaire however the English version of BITE was previously validated on another school population in India.</td>
</tr>
<tr>
<td>Choudry &amp; Mumford (1992)</td>
<td>1 / 2</td>
<td>Yes, defines Muirparis</td>
<td>Selected EAT-26 as it is widely used and proves efficient in detecting ED.</td>
<td>Urdu</td>
<td>Urdu</td>
<td>Set up a translation committee. EAT-26 translated, translated back. Some items rephrased then translated.</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Yes, cross-over design – ensured that any systematic test-retested discrepancies cancelled out. Significant discrepancies were</td>
<td></td>
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<tr>
<td>Study (Year)</td>
<td>Response</td>
<td>Language</td>
<td>Translation</td>
<td>Cultural Orientation</td>
<td>Administered</td>
<td>Interview Conducted</td>
<td>Notes</td>
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<tr>
<td>Mumford, et al (1991)</td>
<td>0 / 3</td>
<td>Not recorded</td>
<td>English</td>
<td>Not recorded</td>
<td>N/A</td>
<td>Not recorded but Interview conducted by two of the authors, who had received training in using DSM-111-R</td>
<td>Acculturation scale developed and validated in a pilot study.</td>
<td></td>
<td></td>
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<tr>
<td>Mumford, et al (1992)</td>
<td>1 / 3</td>
<td>Yes, Pakistani</td>
<td>Questionnaires used identical to the previous Bradford study - cultural questions added</td>
<td>Not translated, as standard of English in the schools was very high, no difficulties</td>
<td>Not recorded</td>
<td>Study information sent to parents asking for their consent</td>
<td>Not recorded</td>
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<tr>
<td>Authors</td>
<td>Score</td>
<td>Definition</td>
<td>Questionnaire Modifications</td>
<td>Validity Assessment</td>
<td>Reliability Assessment</td>
<td>Notes</td>
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<tr>
<td>Srinivasan et al (1995)</td>
<td>4/4</td>
<td>No definition but described as Indian</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Neither of these tools standardised in the Indian population.</td>
<td></td>
</tr>
<tr>
<td>Srinivasan et al (1998)</td>
<td>3/3</td>
<td>No definition but described as Indian</td>
<td>Developed a questionnaire SQ-EDS using the BITE and EAT-40. Main reason – designed for varied and mild form of Eating disorders.</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>The authors argue that the validity of SQ-EDS (newly developed questionnaire) needs further testing in different populations.</td>
<td></td>
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<tr>
<td>Suhail &amp; Nisa (2002)</td>
<td>2/2</td>
<td>No definition but described as Pakistani</td>
<td>EAT-26 and BSQ has shown to be valid and reliable</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>N/A</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Face validity was assessed in a pilot study conducted on postgraduates</td>
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<td>Study</td>
<td>One-stage</td>
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<td>Ahmed et al (1994)</td>
<td>1/3 No definition of the participants ethnicity No</td>
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<td></td>
<td>English English N/A N/A Not recorded Not recorded Not recorded N/A</td>
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<tr>
<td>Button et al (1998)</td>
<td>None Origination form the Indian-subcontinent Included three short vignettes</td>
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<td></td>
<td>designed to assess illness perception and health seeking-behaviour English</td>
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<td>Not recorded N/A N/A Not recorded Not recorded Not recorded N/A</td>
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<tr>
<td>Dolan et al (1990)</td>
<td>None out of 3 Ethnicity was judged from information about the place of birth and parents Not recorded</td>
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<td></td>
<td>English Not included if could not read English N/A First author admin-istered questionnaires N/A Not recorded Not recorded Not recorded N/A</td>
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<tr>
<td>Furnham &amp; Adam-Saib (2001)</td>
<td>1/2 Yes 'British-Asian' was constructed as those from the Indian subcontinent, Indian, Pakistani and Bengali No</td>
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<td></td>
<td>English Not recorded N/A Questionnaires administered by second author N/A Not recorded Not recorded Not recorded N/A</td>
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<td>Furnham</td>
<td>1/2 Ethnicity For the English English N/A N/A N/A Not Not Not N/A</td>
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<tr>
<td>Author(s) &amp; Year</td>
<td>Methodology</td>
<td>Purpose of the Study</td>
<td>Instrument Description</td>
<td>Language</td>
<td>Administration</td>
<td>Response</td>
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<tr>
<td>Patel (1994)</td>
<td>Self recorded</td>
<td>purpose of the study devised questionnaire to investigate the level of integration of Asians into British Society</td>
<td>English</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>N/A</td>
<td></td>
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<tr>
<td>Hill, &amp; Bhatti (1995)</td>
<td>Self recorded</td>
<td>Assessment of cultural orientation added – Mumford et al (1991)</td>
<td>English</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>Not recorded</td>
<td>N/A</td>
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3.9 Discussion

This study systematically reviewed epidemiological studies and the main aim was to examine the prevalence of eating disorders among young South Asian females in the UK and the Indian subcontinent in particular Pakistan, Bangladesh and India. Thirteen studies were identified that met the inclusion criteria. Six were one-stage studies and seven were two-stage studies. Overall, 2,493 South Asian participants were included aged from 9 to 28 years. Participants were recruited from the UK, Pakistan and India. The following section summarises the findings in relation to the review aims, and discuss e.g. limitations of the studies reviewed.

3.9.1 Prevalence of eating disorders in South Asian females

Overall the studies showed that the prevalence of diagnosable eating disorders was greater among South Asian females than among Caucasians living in the UK or among Asian women and girls in the Indian subcontinent. In addition, South Asian females had a higher prevalence of clinical bulimia compared to their white contemporaries (3.4% vs. 0.65) (Mumford et al 1991). Among South Asian girls in the UK, eating disorder symptoms were associated with a more traditional cultural orientation and not with greater Westernisation. The researchers speculated that their findings might reflect the cultural and familial difficulties faced by these Asian girls growing up in the UK.

Two-stage studies conducted in Pakistan and India reported lower prevalence rates of diagnosable eating disorders than reported in Western countries (Mumford et al 1991, Mumford et al 1992, Srinivasan 1995). However this may be due to Western diagnostic tools not being appropriate for capturing symptom patterns present among individuals living in non-Western countries.

Prevalence studies conducted solely in the UK reported Asian participants scoring significantly higher on eating attitude tests compared to Caucasian participants, suggesting that these results do not reflect the low uptake of eating disorder services by South Asian females. However this may be difficult to measure, as often services...
do not record ethnicity (Dolan, 1991). In addition, Srinivasan et al. 2005 argue that it is not possible to determine whether absence of AN relates to failure to meet particular diagnostic criteria of AN.

One-stage studies were unable to report whether British Asian participants had a diagnosable eating disorder as participants were not clinically interviewed and significant differences have not been consistently reported. The limitations of prevalence studies which only use a questionnaire are considerable, even when tests of high sensitivity and specificity are used. Because of the low prevalence of eating disorders in the general population, a test will be of low efficiency in terms of its “positive predictive value”, i.e. the proportion of these identified as cases, will be small (Williams, Hand, Taranolsky, 1980). Furthermore, it can be argued that these studies are more than ten years old, suggesting the need for further research.

3.9.2 Eating Disorders and associated factors

Overall, the studies found that high scores on measuring tools like the Eat-26 for South Asian participants were associated with a more traditional cultural orientation and greater levels of parental control. However, these were measured using structured questionnaires that have been validated on non-Asian population, thus there is a need for qualitative methods of research within this area in order to understand the associated factors for eating disorders among these women.

As the aetiology of eating disorders is complex, there is a need for future studies to focus on other sociocultural factors when carrying out research involving diverse populations. Furthermore, qualitative studies need to be carried out to address how eating disorders manifest themselves and why they develop in this specific population of females. As there is a need to explore these complex issues, the next chapter 3, section 2 will review the qualitative literature on the experiences of South Asian females suffering from eating disorders in the UK and the Indian subcontinent.
3.9.3 Quality Assessment

Quality assessment of studies is an essential part of a systematic review, as it allows examination of the variation in the quality of included studies, (Aos, Phipps, Barroski & Liebi, 2001); because variability in the quality of included studies may account for as much variation in the results of a systematic review's intervention characteristics (Wilson & Lipsey, 2001). The general quality of the reviewed studies was rated as ‘poor’ because of methodological flaws, including poor sample representation and recruitment of participants from one geographical area, educational institutions, and/or high social economic status (especially females in subcontinent studies), therefore one is not able to generalize the findings. In order for findings to be generalised, future studies need to consider participants from other settings like community projects, clinical, as well as educational.

Despite the number of quality measures available, there is no agreement as to which one is best suited (Deeks et al, 2003; Moher et al; 1995; West et al 2002). Some key issues still remain unresolved: which checklist and scales are the ideal approaches (Juni et al 1999) and how the results of quality assessment in a systematic review should be handled in the analysis and interpretation of results (Alderson et al 2004). The STROBE check list (Vandenbrouke et al 2007) was used for the current review because it is widely used. However, Sanderson et al (2007), argued that most of the existing tools lack a rigorous development procedure following standard psychometric techniques. This illustrates the need for further research into quality measures for studies, in particular those with a focus on non-Western populations.

3.9.4 Methodological issues of selected studies

Several methodological issues have arisen and are discussed in turn.

Sample representation

As eleven of the thirteen studies were conducted using high school, college or university students, they were not truly population-based, therefore the findings cannot be generalized. Furthermore, participants from Indian subcontinent
universities were more likely to be from the highest socio-economic status (SES) because they are able to fund their education and studies have shown a link between SES and eating disorder symptoms in ethnic minorities (Polivy & Herman 2002). Therefore SES can be a confounding not sure of meaning variable in studies that report high prevalence of eating disorder symptoms in ethnic minorities.

**Ethnicity**

Also the review studies show a pattern of a lack of specific definitions in relation to ethnicity of the target population and age groups. Cummins et al (2005) also found reviewed studies did not provide detailed information on the ethnic and cultural composition of their participants. This is important, as specific issues to an age group and population can be identified. The method of sampling employed however, is dependent upon the aim(s) of the research. Thus initial sampling needs to be purposeful and guided by the need to select participants that are able to provide relevant data or are “information-rich” (Patton 2002 p203).

**Study design**

Although most of studies used a screening test (EAT) only seven additionally carried out a diagnostic interview (Two-stage studies). Whilst questionnaires can provide evidence of patterns amongst large populations, interview data often gather more in-depth insights on participant attitudes, thoughts, and actions (Kendall, 2008). Cummins et al (2005) suggests accurate diagnosis requires detailed assessment. Although several studies have estimated diagnostic prevalence by evaluating whether individuals meet criteria according to self-report questionnaires, research suggests that a face–to-face interview is necessary to accurately assess for diagnosis (Hsu, 1996). For studies attempting to diagnose eating disorders, it has been recommended a two-stage design where individuals are first screened with self-report measures and then high scorers and a sample of low scorers assessed via a semi-structured interview (Fairburn & Beglin, 1990).

**Cultural quality**

As South Asian participants were included in all of the selected studies a cultural quality check was considered important in order to determine whether they
considered the needs of their participants. In the current review, most studies failed to adequately consider the cultural sensitivity of their participants. For example, many (Bhugra et al (2000), Hill & Bhatti (1995) did not define the ethnicity of the participants being studied or record information on trained interpreters being accessed by the participants. Cultural sensitivity can be viewed as sensitive to the ways in which community members’ values and perceptions about health care differ from his or her own. (Goicoechea-Balbona,1997). Without describing the cultural context on which the client builds their understanding of information, the managed care process will not succeed (Kalnins, 1997).

Translation of screening tools

Even though five studies administered a screening questionnaire in Pakistan and India, only two of the studies translated the EAT questionnaire. Bhugra et al (2000) and Choudry & Mumford (1992) back translated it and only Choudry & Mumford tested its validity in the population under study. However none of these studies specified whether they used trained interpreters. This is important because translators have formal training in interpreting and abide by a professional code of ethics that includes confidentiality, impartiality, accuracy and completeness (Herndon & Joyce 2004). Furthermore, a systematic study suggested that professional interpreters are associated with an overall improvement of care for limited English proficiency patients (LEP). They appear to decrease communication errors, increase patient comprehension, equalize health care utilization, improve clinical outcomes, and increase satisfaction with communication and clinical services for patients with limited English proficiency. (Karliner et al 2007). A major challenge for translators is to ensure literal and conceptual equivalence and comparability at multiple levels of meaning, so it is crucial that they understand both languages and most importantly, know about the cultural understanding of the particular disorder (Bhui et al 2003).

Another approach is translation by an expert committee; alternatively the committee may choose the most appropriate version produced by translators and recommend modifications to maximise face and content validity (Bhui et al 2003). Only Choudry & Mumford (1992) made checks on the quality of the first translation of their questionnaire through a translation committee which resulted in some items being
rephrased and then translated and back translated. In studies which did not make any of these checks, their results could have been due to poor translation rather than cultural factors. However, Srinivasan (1995) recognised that the EAT-40 was not appropriate for the Indian participants, not only because it had not been validated in this sample but because it did not identify individuals with a milder form of eating disorders, and went on to develop a new screening questionnaire (SQ-EDS).

Although researchers have translated such tools to try and increase participants understanding of the questions, it can be argued that assessing eating disorders across cultural populations using measurement tools like the EAT-26 which has been designed and administered in the Western population is difficult, due to lack of awareness about eating disorders. Therefore it can be argued that careful analysis of origins, religion and culture need to be taken into consideration when designing and administering such tools.

Jones et al (2001), recommend forward and back translation by bilingual translators with a reconciliation of the two original language versions. Mumford et al (1991) used six psychiatrists to perform the forward translation into Urdu and six lay bilingual people to back translate. It can be argued that greater numbers of forward translators make the reconciliation more difficult, but conceptual problems are more likely to be identified (Bhui et al 2003). Although there are no definitive guidelines available for the translation process, if the content's semantic and technical equivalences (Flaherty et al., 1988) are assessed for each question, this ensures each item on the questionnaire retains its content and meaning in study cultures and when the questionnaire is used, it is explained and applied in a culturally sensitive manner.

The issue of utilising culturally appropriate tools to measure eating disorder symptoms has been explored (Brown et al, 2000). The development of culturally sensitive tools for South Asians should enable researchers to understand what factors are important in the development and maintenance of an Eating Disorder, as currently they are based on Western culture and may not reflect the full spectrum of eating disorders in other cultures. Cummins et al (2005) argues that the reviewed studies in their research demonstrated that Western based criteria might not as
relevant for populations living in Asian countries. They highlighted the importance of studying symptom patterns rather than diagnostic categories when investigating the presentation of pathological eating in diverse ethnic and cultural populations. Firstly however, research is needed to understand how eating disorders manifest in South Asian populations.

Multicultural communities require valid measures that are culturally sensitive, especially for measures of psycho pathological symptoms leading to a diagnosis and are also crucial to assess recovery and performance of services, and to take account of carer and user views.

**Language and interpreters**

It is important that South Asian participants have a choice of language and interpreters when they participate in research as they need to understand and to feel comfortable about what they want to contribute. Therefore, it is important to identify the participants' preferred method of communication. Dolen et al (1990) did not include participants in his study if they did not read English. Others only offered English to their South Asian participants in Pakistan and India (Mumford et al 1992) as it was thought their standard of English was high because they were from wealthy upper class, therefore other languages, like Urdu were not offered. It can be argued that the exclusion of individuals who cannot speak English is biased and is not representative of the target population and therefore, findings cannot be generalised.

**3.10 Strengths of the review**

The current review has a number of strengths:

- It was a systematic attempt to synthesise the epidemiological research of eating disorders amongst South Asian people. It was conducted systematically, following the MOOSE guidelines (Stroup et al 2000) for reviewing observational studies.
- A specific range of search terms was used based on previous research carried out to select appropriate publications. The researcher carried out an in-depth literature search using different electronic databases and manual searches of journals.
To ensure inter-rater reliability, once these studies were identified by the researcher; together with the supervisor, they then independently applied the inclusion and exclusion criteria and came to a final agreement on which of the studies would be included in the review.

The study’s findings and conclusions were also assessed by more than one assessor. The main researcher and an independent PhD student both independently assessed the findings and conclusions of the selected studies and these studies were summarised using clear and detailed synthesis in order to identify and critically assess methods applied.

Cultural sensitivity of the methods used by the selected studies was assessed. This has not been reported elsewhere to the researcher's knowledge and represents a methodological advancement on other reviews in the field.

3.1 Limitations of the review

The main limitation of this review was that only studies published in English were considered which may have limited the number of studies included. Although the inclusion of studies written in Urdu, Hindi and Bengali would need to be translated into English which would have been time consuming and costly, they may have offered further insight into the prevalence of eating disorders among Asian females and the tools administered. It should be noted however that no such study appeared in the searches.

3.12 Future research

In the light of the findings in this review, there remains a need for further and better research to be conducted on the prevalence of eating disorders among South Asian females from different SES. non-suburban participants from the Indian subcontinent are required, using screening tools that have been validated and tested for their reliability within this particular population. Future studies should adopt transparent sampling methods, providing clear descriptions of participant samples, recruitment from various organisations (for example, community, educational organisations and clinical and non-clinical patients), type of methodological approach, data collection
and analysis procedures. Results should be described with reference to widely accepted and credible methods for ensuring the quality of the findings. These considerations will result in the development of a clearer understanding of prevalence of eating disorders among South Asian females. Furthermore, there is a need for more research in order to understand the particular factors behind eating disorders among this group.
3.13 Summary of systematic review findings

This chapter reported the systematic review of observational/epidemiological studies of South Asian individuals in the UK and subcontinent. Overall the studies show that the prevalence of diagnosable eating disorders is greater among South Asian females than among Caucasians living in the UK, or than among South Asian in the India subcontinent. Furthermore, South Asian females reported eating disorders symptoms and bulimia significantly more than Caucasian females, although this may vary depending on the population being studied. The findings also suggested that prevalence of eating disorders is increasing among ethnic minorities and in non-Western countries, though the low methodological quality of the studies means it is difficult to draw clear conclusions and findings made are unlikely to generalise beyond the higher SES groups that were sampled. Consequently, it is unclear precisely how vulnerable South Asians are to eating disorders. In addition, literature on eating disorders among South Asian people is limited due to the variable quality of the small number of past studies. These findings were consistent with previous reviews in this area of research: Cummins et al (2005) and Brown et al (2009).

From this review we can ascertain that South Asian females are not immune to developing eating disorders and that cultural factors seem to be important in the development and the maintenance of eating disorders among them. This warrants additional and better quality epidemiological research with careful consideration of the origin, religion, and culture of the studied population. Despite increasing recognition of the prevalence of eating disorders among South Asian females not only those living in Western countries but also among those living in their countries of origin, there is inadequate research into the development and treatment of eating disorders among this group of females. There is very little evidence relating to the experiences of South Asian females with eating disorders, or to their uptake and experiences of services. Although the quality of past studies is variable and they are out-dated, they are sufficient to prompt attention. In order to understand and explore the experiences of these groups of females further there is a need for qualitative research. Therefore, in the following chapter, the researcher carried out a systematic
review of qualitative studies of eating disorders carried out among this group of women in the UK and the Indian subcontinent.
Chapter 4

Study 2- Systematic review of qualitative studies of eating disorders among South Asian females in the UK and the Indian subcontinent.
4.1 Overview

Increasingly eating disorders are being described in different ethnic and social groups (Mumford, 1993; Brayant-Waugh & Lask, 1991; Lee, 1991). Rates of eating disorders appear to vary among different ethnic groups. In the previous chapter, a systematic review of quantitative studies reported that there is prevalence of eating disorders within South Asian populations in the UK and the Indian subcontinent (Dolan et al., 1990, Mumford et al 1991, Suhial & U-Nisa 2002). Over all these studies findings report a higher prevalence of bulimia than anorexia among South Asian females in the UK (Mumford et al 1991) as well as the Indian subcontinent (Mumford et al 1992, Choudary & Mumford 1992, Suhial & U-Nisa 2002) compared to Caucasian females.

Despite these figures, there have been no published reviews on qualitative studies examining the strength of evidence for eating disorders in South-Asian populations. There is a need to review existing qualitative research on the views of South Asian females with eating disorders in order to develop our understanding of their needs and expectations. Qualitative methods of research should be valuable to understand these complex relationships, as qualitative interview data often reveal more in-depth insights on perceptions attitudes, thoughts, and actions (Kendall, 2008).

Previous reviews of qualitative research around eating disorders has mainly focused on the views of patients around treatment (Sinh & Warfa, 2013) or experience of women who are pregnant with an eating disorder but these studies have not given a breakdown of ethnicity (Tierney, 2013). Qualitative studies have mainly explored help-seeking behaviours (Hepworth & Paxton, 2007) and have not included British South Asian females focussing mainly on Caucasian females and other ethnic groups (Becker et al 2010). The literature on British South Asian females with eating disorders presenting to services has mainly been on case reports, Lacey and Dolan (1988) first reported a case of bulimia in a British Asian girl. Bhadrinath (1990) reported three cases of Asian adolescent anorexia nervosa and Bryant-Waugh and Lask (1991) described four cases of Anorexia nervosa in children growing up in the UK. Furthermore qualitative studies that have examined the views of South Asians
have explored other illnesses and disorders for example, asthma, self-harm and
Chronic fatigue syndrome, Diabetes and mental health (Rooney et al, 2011; Chew-

The current chapter reported a systematic review of qualitative studies reported in
the literature on the experiences of South Asian females diagnosed with an eating
disorder in the UK and/or the Indian subcontinent. The intended focus of the review
was to explore factors in the development and maintenance of the disorder and
identify potential phenomena to help understand the higher prevalence levels found
in the previous chapter. Therefore this review focused on reviewing data that
explores, or potentially explores, the development and maintenance of eating
disorders. It aimed to include all qualitative studies of eating disorders among South
Asian females in the UK and in the Indian subcontinent screened as relevant in the
review.

Aim of the review

This systematic literature review aimed to:

a) Review evidence of qualitative studies on South Asian females with eating
disorders
b) Review the methodology employed within studies included in the review
c) Consider the quality and cultural sensitivity of included studies.
d) Conduct a meta-synthesis of extracted data, should the quality and quantity
of the data permit this.

4.2 Method

To identify relevant studies specific search terms were applied in PsychINFO, Medline, CINAHL & EMBASE (1806 – 2011 and again in 2014). The initial search
was conducted in 2011 and an updated search was conducted in September 2014 to
incorporate any recently published studies.

4.2.1 Search terms for systematic review of literature

The search terms listed in Figure 3 ($=$ with wild cards when necessary) were used
when devising search strategies for electronic databases. The selection for search
terms was undertaken with advice from literature search services at the University of Manchester Library and review of search strategies developed for ethnic minorities by other publications, for example; Feder et al 2006, who carried out a meta-analysis of qualitative studies of women exposed to intimate partner violence. Studies to be considered for retrieval were recorded on Endnote. To make sure that any relevant studies were not missed the researcher also hand-searched the references lists of all studies screened at full text retrieval and other key texts of eating disorders. The process for searching was undertaken in 2 phases (see below).

Phase 1

Search term 1-6: The eating disorder search terms that were used are covered by ICD 10 and DSM IV; these terms have also been used in South Asian developing countries and ethnic minorities.

Search term 8-21: Ethnicity, search terms were selected to include as any variations in the way ethnicity is reported in published research. Names of individual South Asian countries were also used as search terms.

Search term 23-33: young females, to select studies that included young females.

Search term 35-54: qualitative, to ensure only qualitative studies were selected

Phase 2

Combining search terms:

To combine each term “OR” was used, (or/1-6, or/8-21, or/23-33, or 35-54) and then to combine these “AND” was used,( 7and22and 34 and 55).
Figure 3. Key search terms

1. exp Anorexia Nervosa/
2. exp Binge Eating Disorder/
3. exp Bulimia Nervosa/
4. eating disorder$.
5. anorectic.mp.
6. bulimic.mp.
7. anorex$.mp
8. binge eating.mp.
9. (eating disorder$ or bulimic or anorectic or anorex$ or binge eating).ab,ti.
10. or/4-9
11. South asian.mp.
12. pakistani$.mp
13. india$.mp.
14. Bangladesh$.mp
15. punjab$.mp.
16. bengal$.mp.
17. bangladesh$.mp.
18. kashmir$.mp.
19. mirpur$.mp.
20. gujrat$.mp.
21. or/11-20
22. Schoolgirls$.mp.
23. female$.mp.
24. woman.mp.
25. Women.mp.
26. girls.mp.
27. young.mp.
28. teen$.mp.
29. child$.mp.
30. juvenile.mp.
31. young adult$.mp.
32. or/22-31

1-9
Eating Disorder
search terms

10. or/4-9
11. South asian.mp.
12. pakistani$.mp
13. india$.mp.
14. Bangladesh$.mp
15. punjab$.mp.
16. bengal$.mp.
17. bangladesh$.mp.
18. kashmir$.mp.
19. mirpur$.mp.
20. gujrat$.mp.
21. or/11-20
22. Schoolgirls$.mp.
23. female$.mp.
24. woman.mp.
25. Women.mp.
26. girls.mp.
27. young.mp.
28. teen$.mp.
29. child$.mp.
30. juvenile.mp.
31. young adult$.mp.
32. or/22-31

11-20
South Asian countries
& terms for ethnicity

10 and 21 and 32

22-31
female & age search
terms

33. Qualitative research.mp.
34. Grounded theory.mp.
35. Content analysis.mp.
36. Discourse analysis.mp.
37. naratives.mp.
38. qualitative.tw.
39. ((ethnographic or ethnological or ethnology) adj2 (research or study)).tw.
40. (grounded adj2 (theor$ or study or studies or research or analysis)).tw.
41. ((theme or thematic or themes) adj2 analysis).tw.
42. content analysis.tw.
43. constant comparative method$.tw.
44. field notes.tw.
45. participant observation.tw.
46. narrative analysis.tw.
47. (naturalistic adj2 field study).tw.
48. (audiorecording or audio recording).tw.
49. focus group$.tw.
50. (conversation analysis or discourse analysis).tw.
51. hermeneutic.tw.
52. ((phenomenology or phenomenological) adj2 research).tw.
53. (semi-structured adj2 (question$ or interview$)).tw.
54. (key informant adj2 (question$ or interview$)).tw.
55. ((unstructured or un-structured) adj2 (question$ or interview$)).tw.
56. (tape recorded or tape recording).tw.
57. ethnonursing.tw.
58. lived experience.tw.
59. ((life or womens) adj2 (story or stories)).tw.
60. Life world$.tw.
61. ((theoretical or purposive) adj1 (sample or sampling)).tw.
62. or/33-61
63. 10 and 21 and 32
64. 10 and 21 and 32 and 63
4.2.2 Literature search procedure

Literature search was carried out using three methods listed below (also see figure 2):

A: Electronic search strategy

The following electronic databases were searched:

- Medline – from 1948 to Aug 2014
- CINAHL (cumulative index to nursing & allied health literature)
- PsycInfo – from 1806 to Aug 2014
- EMBASE- from 1974 to Sep 2014

B: Google search first 100 references

C: Hand search: reference lists of all included studies

Inclusion and Exclusion criteria

Studies were included if they met the following criteria:

- Study includes views of such females within UK or Indian subcontinent (particularly Pakistan, India or Bangladesh).
- Study included a stated aim to explore the perceptions and experiences of South Asian females with eating disorders, of eating disorders and services.
- Study must use data collection methods that are qualitative

Studies were excluded for the following reasons:

- Study fails to report both its data collection
- Studies not written in English
- Case and/or clinical studies
- Study not qualitative

4.3 Process of data extraction

Selection procedure

The inclusion and exclusion criteria listed above for screening and selection were driven by the main aim of the review. Inclusion and exclusion criteria were applied successively to titles abstracts and full text. Full reports were obtained for those studies that appeared to meet the criteria or where there was insufficient information to be certain. The initial selection was broad to ensure that as many studies as
possible were assessed as to their relevance to the review. The numbers of articles included or excluded at the various stages were noted (see figure 4).

The screening and selection procedure
Abstracts and titles that clearly had no relevance to the aim of the review were excluded by the researcher. Potentially relevant studies were then accessed and read in full to ascertain if they met inclusion criteria. None of the studies met the inclusion criteria for one or more of the following reasons; they only reported quantitative data and did not utilise qualitative methods and/or they were clinical/case studies. The excluded 4 studies only invited the participants for an interview to determine whether they had an eating disorder according to the Diagnostic and statistical manual of mental disorders of the American Psychiatric (Mumford et al; 1992, Srinivasan et al (1995), Srinivasan et al (1998).
**Figure 4: Flow diagram of Search strategy used to identify and screen relevant qualitative studies**

- **Identification**: MEDLINE (n=173), Psycinfo (n=96), Embase (n=519), CINHAL (n=26)
- **Total studies identified through database searching (n =814)**
- **Additional studies identified through other sources (n =0)**
- **Duplicates removed (n = 23)**
- **Abstract of studies screened (n =791)**
- **Studies excluded with reasons:**
  - they were clinical/case studies
  - they examined prevalence
  - participants were not South Asian
  - no qualitative data (n=784)
- **Full-text articles assessed for eligibility (n = 7)**
  - Full-text articles excluded:
    - No qualitative data (n =4)
- **Studies included in qualitative synthesis (n = 3)**
4.4 Quality Assessment

There are no definitive guidelines on assessing the quality of qualitative research: a plethora of tools exist with the aim of fulfilling this objective (Walsh & Downe, 2006). The quality of the studies was appraised in accordance with the Critical Appraisal Skills Programme Criteria (CASP 2013) qualitative research check list (Appendix 2) and guidelines developed by Walsh and Downe (2006; Appendix 3), in order to assess different aspects of methodological and increase interpretive rigor. These criteria consider: the appropriateness and coherence of the study scope, design, sampling strategy, analysis and interpretation and studies are rated on the criteria from A-D: Category A (high) for studies with a score of 17 or above; Category B (medium) for studies with a score between 11 and 16; Category C (low) for studies with a score of less than 11. All included studies were scored according to this criteria and categorised as A, B or C (see table 11). An inter-rater reliability check was conducted on this and demonstrated 100% agreements between the supervisor and the researcher.

4.5 Results

Synthesis of findings
In total 183 participants was interviewed aged between 14 to 24 years old. Suhail and Zaib-u-Nisa (2002) interviewed all their participants whereas Mumford et al (1991) and Bhugra et al (2002) only interviewed those who scored above 20 on the EAT-26. Each of the three studies were read thoroughly to identify key concepts and access quality according to CASP (2013) and were all rated as poor, because none of the studies have applied any real qualitative methods thus the researcher was unable to synthesis the studies. However although these are of low quality they did draw upon some of the perceptions of their participants and this was considered to relevant to this review no matter how small-scale the research. Only one study Bhugra et al (2000) identified themes, when fifty Indian participants with eating disorders were asked about the role of the family and their identity, participants saw this as:

1. Inextricably linked with being part of their family
2. Individuals saw themselves as being defined by their personal relationships,
3. The difficulty in defining themselves outside of these relationships

Although Mumford et al (1991) did not identify themes in order to expand on their survey they used an account written by a 19 year old girl from a Pakistani Muslim family (see appendix 4) who developed anorexia. She talks about facing ‘culture clash’ and being controlled by her parents and states:

“I am facing what is called ‘culture clash’. In school I was prepared how to handle my life and how to stand up for myself, while when I went home I was expected to be quite, submissive, obedient and totally dependent on my parents”.

“I don’t know why I should do as the parents and family asks- they have all enjoyed their lives and now they want to control mine”.

Mumford et al (1991) identified two main contributing factors as reasons for the most traditional girls experiencing the greatest internal conflict; around issues of identity as they grew up with two sets of cultural values and argue: it might be that the greater the difference between the two cultures, the greater the internal conflicts and anxieties which arose. Another contributing factor could be greater rigidity of family functioning within the more traditional families, leading to greater intergenerational conflict (Mumford et al 1991).

Synthesis of qualitative literature is increasingly common within health research (Ring et al 2010). The intention had been to follow the guidance of Noblit & Hare (1988) whose method is widely used for synthesising qualitative data (Britten et al., 2002). However, synthesis could not be carried out any further as the study did not record any details of the qualitative research methods they applied to the interview data.
Table 11: Overview of studies with quality rating

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Sample Characteristics</th>
<th>N</th>
<th>Data Collection</th>
<th>Diagnosis</th>
<th>Data Analysis</th>
<th>Themes</th>
<th>Quality rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bhugra et al (2000)</td>
<td>India</td>
<td>All females aged between 15 - 23 yrs</td>
<td>Total sample was 504 of which 50 were interviewed</td>
<td>One-to-one interviews</td>
<td>No one scored on the DSM-III-R interviews as having eating disorders.</td>
<td>Not recorded</td>
<td>When asked about the role of the family and their identity, three key themes emerged: 1. Inextricably linked with being part of their family. 2. Individuals saw themselves as being defined by their personal relationships. 3. The difficulty in defining themselves outside of these relationships</td>
<td>C : Poor</td>
</tr>
<tr>
<td>2. Mumford et al (1991)</td>
<td>UK</td>
<td>All females aged between 14 -16yrs</td>
<td>22 Asian 32 Caucasian</td>
<td>Not recorded</td>
<td>7 Asian – Bulimia 2 Caucasian – Bulimia 1 Asian – Anorexia 2 Asian – EDNOS 4 Caucasian - EDNOS</td>
<td>Not recorded</td>
<td>No themes identified – but gave a sample of interview in appendix 4</td>
<td>C: Poor</td>
</tr>
<tr>
<td>3. Suhail &amp; Zaib-U- Nisu (2002)</td>
<td>Pakistan</td>
<td>All females aged between 18-24 yrs</td>
<td>111 Pakistani</td>
<td>Not recorded</td>
<td>2 – Bulimia 2- EDNOS</td>
<td>Not recorded</td>
<td>No themes identified – but gave quotes in the discussion section of the article</td>
<td>C: Poor</td>
</tr>
</tbody>
</table>
4.6 Discussion

The selected studies, although of poor quality, did identify important themes for example, cultural conflict (Mumford et al, 1991) and controlling family (Bhugra et al, 2002, Mumford et al, 1991). In the light of the lack of studies in this review and the poor quality of the selected studies, there remains an urgent need for qualitative studies to explore the views and experiences of South Asian females with eating disorders. The main issues that need to be explored are: perceptions and experiences of South Asian females with eating disorders in relation to treatment, health care professionals, family and cultural issues. In addition there is a need for further qualitative research into the experiences and views of family members and health professionals’ views and experiences of the treatment for eating disorders among South Asian females as the involvement of these populations’ experiences will aid to modify services to meet their expectations and increase treatment accessibility (DOH, 1999, 2004). Further, The National Institute of Clinical Excellence (NICE, 2004), highlights the importance of patient and carer satisfaction in the assessment of treatment effectiveness for eating disorders. The importance of service users’ views has also been recognised in fulfilling the governments’ agenda of ‘Delivering Race Equality in Mental Health Care ‘(Department of health 2005).
4.7 Summary of review findings

Thus given the evidence of British Asians as an at risk population for eating disorders similar to Caucasian counterparts (Mumford et al. 1991), and the lack of qualitative research, a qualitative study of improving understanding and access to treatment for eating disorders among young British South Asian females was carried out (Chapter 4 -Study 3). This will explore the perceptions and experiences of British South Asian females through qualitative methods of research; by one-to-one interviews with service users, family members and health care professionals with the aim of increasing understanding of the psychosocial factors that South Asian females with eating disorders perceive to be important in the development and maintenance of their eating disorder and difficulties that they experience in accessing services. This research can also contribute to understanding specific needs of South Asian females in terms of cultural competent services.
Section 4

Qualitative Study 3

A qualitative study of, the experiences and perceptions around eating disorders, of South Asian females with eating disorders, family members and health care professionals.
5.1 Rationale

According to MIND (2006) British South Asians experience difficulties in accessing mental health services due to inappropriate treatment and limited availability of services that cater specifically for the needs of Asian individuals suffering from psychological distress. Studies have reported that South Asians do experience mental health difficulties (Nazroo, 1997; Anand & Cochrane, 2005). The National Institute for Clinical Excellence and Mental Health (NICE, 2004) reported that most mental health services have struggled to meet the needs of ethnic minority people. There is also a high incidence of psychological distress among South Asian women with mental health difficulties such as eating disorders (Bhugra & Bhui, 2003). Epidemiological studies suggest that the rates of clinical eating disorders in ethnic minority groups are lower than those reported in Caucasians (Brown, Cachelin & Dohm, 2009). However research examining prevalence of eating disorders in Asian populations, particularly British South Asians suggest a similar level of risk of eating disorders to Caucasian populations (Cummins, et al, 2005). Research that has used qualitative methods to examine factors and influences contributing to eating disorders have been predominantly carried out with participants from a Caucasian background. If health care providers are to develop their services to meet the needs of South Asian females with eating disorders, there is a need to understand more fully the factors contributing to both the onset of eating disorders and the willingness to access services. However despite the apparent increase in the development of eating disorders among South Asian females, to date no studies have investigated, using qualitative methods of research, the development and maintenance of eating disorders among these females.

The systematic reviews (see Section 3, Chapter 3-4) show limited research into the prevalence of eating disorders among South Asian females and little to no qualitative research, in relation to the views of these women with eating disorders’ experiences and their journey towards recovery. Increasing acknowledgment of the utility of qualitative research can enrich understanding of eating disorders through engagement with sufferers and service providers. This study attempts to fill this gap through exploring issues relating to help seeking and barriers to access to treatment for eating disorders among young British Asian females, by using qualitative
methods of research. Qualitative methods were used because the study sought to establish the perspectives of these women, Asian parents and health care professionals on eating disorders within the South Asian community. This utilised one-to-one interviews with service users, family members and health care professionals with the aim of increasing understanding of the psychosocial factors that these women perceive to be important in the development and maintenance of their eating disorder, and difficulties that they experience in accessing services.

The perspectives of parents/siblings will be researched to highlight their understanding around eating disorders and also their journey into caring for their daughter/sister with Eating Disorders. Also how this role impacts on the potential maintenance and recovery of the individual suffering from Eating Disorders. This will contribute to the understanding of eating disorders in a socio-cultural context.

The importance of delivering culturally competent care has been documented in policy guidance (Department of Health, 2005). Therefore researching the views of health care professionals would determine their perspectives around South Asian females and eating disorders highlighting their experiences, concerns and barriers around treating these groups of women. Such research can contribute to defining the culture specific needs for South-Asians with eating disorders in order to aid cultural competence in health care professionals.

Questions that emerge are whether British Asian females exposed to Western views, yet living within their own culture, appraise their bodies in a similar ways to Caucasian females and what lies behind the high rates of eating disorders in these Asian females. In an attempt to answer these questions the researcher conducted a qualitative study with South Asian females living in the UK but from Indian, Pakistani or Bangladeshi culture but theoretically exposed to Western cultural ideals through living in a Western country. The main aim of this research was to explore the personal experiences of cultural stress and eating habits among these groups of females.

**Aims**

The main aims of this study were to understand the issues relating to eating disorders and South Asian females through:
a. Exploring their perceptions in respect of their experience of health care and their views on the role of family in facilitating or as obstacles to receiving effective care.

b. Examining perceptions and understanding the family members around eating disorders and their experiences of living or caring for a family member suffering from an eating disorder.

c. Exploring perceptions of health professionals, including experiences of providers of services for eating disorders, about potential barriers and facilitators to accessing care for this population.

5.2 Methods

This section presents the research methodology and the consideration of the main ethical issues. Approval for the study was obtained from the National Research Ethics Service (NRES) Committee North West – Greater Manchester Central.

Design

It was decided that a *qualitative semi-structured* method would be the most appropriate means of exploring the subjective experiences of the participants. The study aimed to recruit a total of 60 participants to take part in individual semi-structured interviews. All were identified either by themselves or professionals involved in supporting individuals with mental health issues.

Setting for the study

The study was conducted in Greater Manchester (GM) because according to the census 2001-2011, 20% of GM’s population belong to non-white British ethnic groups of which the Pakistani community is the largest and accounts for 4.8% of GM’s population compared to 2% in England & Wales (see table 12). Manchester’s ethnic population growth was the highest for any major provisional city at 19% giving a total of population for Greater Manchester 2,682,500 (New Economy Census 2011).
Definition of ‘South Asian’
For the purposes of the current study the term ‘South Asian’ is confined to young women whose ancestry is in the countries of the Indian subcontinent, including India, Pakistan, and Bangladesh who are living in the UK.

Table 12: New Economy Census 2011

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage</th>
<th>Compared to England &amp; Wales average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pakistani</td>
<td>4.8%</td>
<td>1.86%</td>
</tr>
<tr>
<td>Indian</td>
<td>2.0%</td>
<td>2.30%</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>1.3%</td>
<td>0.71%</td>
</tr>
<tr>
<td>White British</td>
<td>80%</td>
<td>87.27</td>
</tr>
<tr>
<td>Other</td>
<td>11.9%</td>
<td>7.96</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

5.2.1 Why use qualitative methods of research for the current study?

Qualitative methods embrace the uniqueness of human experience (Henwood & Pidgeon 1993) and do not attempt to limit participants to a controlled set of answers. Therefore as this research sought to explore individual experiences and relationships around eating disorders it was decided that qualitative methods of research, utilising interviews would be used, Qualitative research is concerned with how people experience and make sense of specific events in their lives. It allows for exploration of the meaning attributed to events to provide a rich description of the experience and acknowledges the active role of the research process (Willig, 2001). Applying qualitative methods would be particularly useful for these particular groups as this will allow for understanding of the main issues around eating disorders and young Asian females.

The application of a quantitative methodology was not applied because it is constrictive and applies closed ended questions and looks to test a hypothesis. This can be appropriate for some research but for this study qualitative methods allow more flexibility with open ended questions where participants are free to respond in their own words rather than simply give “yes” or “no” answers. Maxwell (1996) suggests that qualitative studies aid the understanding of the meaning of events for an individual, as well as the context of their related actions, rather than simply
addressing the outcomes of these actions, as very often the case with quantitative research.

Peters (2012) goes further in stating that there are a number of scientific, practical and ethical reasons why mental health is an area that can particularly benefit from qualitative inquiry, as qualitative methods provide a way of giving voice to participants. This is particularly important for minority group such as South Asian in the current study as it will allow them to express their experiences and feelings in a safe and controlled environment. The qualitative method offers an effective way of involving service-users in developing interventions for mental health problems (Medical Research Council 2008). Qualitative studies have been utilised to establish the users’ needs and mental health services can meet them; for example Pandya & Herlihy (2009) conducted a study on South Asians views on family therapy, and found that safety in front of the therapist and emotional connection to the therapist (including feelings towards the reflecting team and consideration of ethnically matching therapist and client) is important. In general, the quality of the alliance is seen as more important than employing culturally specific techniques. Gilbert & Sanghera (2004) studied South Asians use of mental health services and found that fear of reflected shame and loss of izzat (honour) were regarded as key reasons South Asian women might not use mental health services. A central fear was of a failure by professionals to keep confidentiality.

**Consideration of approaches to collecting data**

Bannister et al (1994) suggests interview-based research permits the researcher to access the subjective meanings of the participants and at the same time permit an element of sensitivity in the investigation. Interviews allow the exploration of complex issues, such as ambiguities, contradictions and gaps which can be addressed, and new areas raised by a participant can be explored with relevant questions. They also force the researcher to identify their own involvement in the research and to address the power issues in the relationship.

Interviewing also has face validity as a research tool to participants and this was felt to be important as this method would improve credibility and authenticity of the
research and consequently permit greater access to the target population (Maxwell 1994). A semi-structured interview technique was used to conduct the interviews. This method has a schedule of relevant topics and during the interview the researcher can use both directive and non-directive questions, producing answers on both a general and a more detailed basis (Hammersley & Atkinson 1983). Furthermore Coolican (1994) suggests that the semi structured interviewing increases the consistency of the data while retaining a high degree of richness and enabling more systematic analysis. Semi-structured interviewing allows the researcher the flexibility to explore issues other than those on the interview guide whilst imposing some structure regarding the discussion of certain themes. Hence this type of interview provides more scope than the structured method and provides richer and more detailed data than questionnaires. In addition it reduces the amount of irrelevant information which may be obtained in unstructured interviews.

Field & Morse (1996) argued that semi-structured interviews also permit the exploration of complex personal and sensitive issues which would be difficult to target through questionnaires. Moreover the use of probes such as ‘Can you tell me a little bit more about it’? Provides the researcher with the opportunity to clarify and expand on issues raised by the interviewees. More importantly, this methodology provides the researcher with the necessary tool to obtain a full and detailed account from the interviewees based on their interpretations and viewpoints. It was felt that face to face interviews were better than interviewing over the phone as the physical presence of the interviewer means that a range of non-verbal channels of communication are available. The interviewer may detect signs of misunderstanding and frustration on the part of the respondent and react to these more easily and. finally, face-to-face respondents are less likely to be engaged in other activities while answering questions and interviews are typically carried out at a slower pace than over the telephone.

Although focus groups were considered, it was believed that this approach might disadvantage quieter, less confident individuals and importantly compromise the confidentiality of information provided by the participants. The option for a structured interview was rejected on the grounds that it would be inherently rigid and inflexible (Cohen et al., 2007). However Thomas (2009) explains that structured
interviews ensure a certain degree of standardisation and therefore data can be more easily compared. Brennan (1988) argued that a non-directive approach allows the participant a larger degree of control over the content interview and allows the interviewee to freely give the amount of information they want to give and not information which is biased by the interviewer. Therefore, allowing the participant greater control avoids the imbalance of power relationships that have characterised traditional research where the interviewer has been the one in control (Oakley, 1981).

It might also be argued that unstructured interviews are the only way to gain the true picture of the situation and they allow the participant to consider the important issues, which ensures that the researcher keeps an open mind (why ensures) (Thomas 2009). Unstructured interviews were considered for this study, however, because certain areas and topics (please see appendix 5-7, interview schedule & questions) need to be covered in order to address the research questions in short-time scales, semi-structured interviews were eventually considered to be the most appropriate. With this in mind, and consideration of the research questions of this study, it was judged appropriate to adopt a qualitative method and analysis. It was that hoped this would allow for the emergence of a rich description of the participants' experience from which themes could be generated.

5.2.2 Justification of using thematic analysis in the current study

Thematic analysis is a method of analysis that aims to identify, analyse and report salient patterns of meaning that occur within a data set (Braun & Clarke 2006). In contrast to other qualitative methods such as grounded theory (Martin et al 1986) and Interpretative phenomenological analysis (IPA), (Smith et al 1999), thematic analysis is not bound to a specific theoretical framework (Aronson 1994).

Thematic analysis (TA) was chosen for data generation through analysing the interview transcripts, because it both seeks to understand human experience and is a way of organising interview material in relation to specific research questions. Furthermore, it involves the searching across a data set, be that a number of
interviews or focus groups, or a range of texts in order to identify repeated patterns of meaning (Braun and Clarke, 2006).

5.2.3 Why not a different qualitative analysis?

When considering the most appropriate methodology for this research, other qualitative approaches were considered. These included Grounded Theory (GT) and Interpretative Phenomenological Analysis (IPA). IPA is a method of analysis closely attached to a phenomenological epistemology (Smith & Osborn, 2003). Based on the assumption that people will try to make sense of their experiences, IPA aims to hear people’s experiences of reality in order to understand a particular phenomenon and provide a description of how this might be done (Smith, Flowers, & Larkin, 2009). Smith & Osborn (2003) argue that this approach can allow the researcher to both understand the participant’s view, while at the same time add interpretation and ask critical questions of the data. GT can be seen to involve aspects of a more sociological approach (Willig 2008), focusing on patterns within data that can support broader conceptual explanations. A GT analysis can be approached in a number of ways. However, the overall aim is to generate a theory that remains ‘grounded’ in the data (McLeod, 2001). GT therefore, follows an inductive approach to analysis, where data collection and analysis are undertaken simultaneously (Strauss & Corbin, 1990).

Braun and Clarke (2006) argue that as TA does not rely on any pre-existing theory, it can be used within a wide range of theoretical frameworks, and avoid being driven as much by the researchers’ own interests or pre-designed criteria. Themes can therefore occur which may not appear directly linked to questions asked. Additionally, guidelines and stages of analysis outlined in the approach allows for clarity and transparency in the analysis process (Braun & Clarke, 2006).

The aim of the current research was to develop an understanding of the issues relating to barriers to accessing help and treatment for eating disorders among young British South Asian females by highlighting family and cultural issues, parents/sibling particular aspects and views about living with a daughter/sister with an eating disorder and also perceptions of health care professionals about potential
barriers and facilitators to accessing care for this population. The focus of this research was therefore aimed to be broader than that of the individual experience and thus it was felt the flexible nature of TA could allow for greater emergence of unanticipated findings and understanding of individuals within a wider context (Marks & Yardley 2004), including their family systems.

5.2.4 Participants

There were three groups of participants, South Asian females experiencing eating disorders (service users), family/siblings and health care professionals. Table 13 (see below) lists the inclusion criteria and Table 14 shows the exclusion criteria for participants.

**Table 13: Inclusion criteria for patient, parent/sibling and health professional.**

<table>
<thead>
<tr>
<th>South Asian females</th>
<th>Family / Sibling</th>
<th>Health Professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female with eating disorders aged 18 or over – In order to characterise the sample before the interview these females completed an Eating Disorder Examination Questionnaire EDEQ (Fairburn &amp; Belglin 1994) – Please refer to table 15.</td>
<td>A relative of a female currently suffering or suffered with an eating disorder.</td>
<td>Must be from a UK mental health background – Medical Doctor, counsellor, Psychotherapist, community mental health worker etc</td>
</tr>
<tr>
<td>English speaking and non-English speaking (but can speak Urdu or Punjabi as researcher fluent in all three languages) as women who have recently arrived to the UK may also be eligible to take part in the study.</td>
<td>English speaking and non-English speaking (but can speak Urdu or Punjabi) as parents/sibling who have recently arrived to the UK.</td>
<td>Have experience of working with South Asian females</td>
</tr>
<tr>
<td>Have an eating disorder of a restrictive type: Anorexia Nervosa; Bulimia nervosa; Eating Disorder Not Otherwise Specified (EDNOS). This was determined by the Eating Disorder Examination Questionnaire (EDE-Q) – (Fairburn &amp; Cooper, 1993) please see appendix 15.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participants did not have to be identified by a clinical team (they could self-refer to take part in the study) or have to be receiving treatment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Asian specifically Pakistani, Indian or Bangladeshi.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All participants must provide consent to be interviewed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All Participants must be from the Greater Manchester area</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 14: Exclusion criteria

<table>
<thead>
<tr>
<th>South Asian female</th>
<th>Parent/sibling</th>
<th>Health Professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>Non South Asian</td>
<td></td>
</tr>
<tr>
<td>Under 18 year olds were excluded as the ethics committee did not permit the researcher to interview this age group. Also there would be an issue of getting consent from the parents this may breach confidentiality.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participants deemed too unwell to participate.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 15: Eating Disorder Examination – Questionnaire (EDE-Q) scores of South Asian females to determine eligibility for current study

Key: No days = 0, 1-5 days=1, 6-12 days=2, 13-15 days=3, 16-22 days=4, 23-27 days=5, Every day=6.

<table>
<thead>
<tr>
<th>EDE-Q Subscale ITEMS</th>
<th>Participant’s scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ED1</td>
</tr>
<tr>
<td><strong>Restraint</strong></td>
<td></td>
</tr>
<tr>
<td>1 Restraint over eating</td>
<td>6</td>
</tr>
<tr>
<td>2 avoidance of eating</td>
<td>6</td>
</tr>
<tr>
<td>3 Food Avoidance</td>
<td>5</td>
</tr>
<tr>
<td>4 Dietary Rules</td>
<td>4</td>
</tr>
<tr>
<td>5 Empty Stomach</td>
<td>5</td>
</tr>
<tr>
<td><strong>Eating Concern</strong></td>
<td></td>
</tr>
<tr>
<td>6 Preoccupation with food, eating or calories</td>
<td>5</td>
</tr>
<tr>
<td>7 fear of losing control over eating</td>
<td>5</td>
</tr>
<tr>
<td>09 Eating in secret</td>
<td>5</td>
</tr>
<tr>
<td>34 Social eating</td>
<td>4</td>
</tr>
<tr>
<td>15 Guilt about eating</td>
<td>4</td>
</tr>
<tr>
<td><strong>Shape Concern</strong></td>
<td></td>
</tr>
<tr>
<td>10 Flat stomach</td>
<td>6</td>
</tr>
<tr>
<td>11 Preoccupation with shape or weight</td>
<td>4</td>
</tr>
<tr>
<td>30 Importance of shape</td>
<td>4</td>
</tr>
<tr>
<td>12 fear of weight gain</td>
<td>5</td>
</tr>
<tr>
<td>33 Dissatisfaction with weight</td>
<td>6</td>
</tr>
<tr>
<td>35 Discomfort seeing body</td>
<td>4</td>
</tr>
<tr>
<td>36 Avoidance of exposure</td>
<td>5</td>
</tr>
<tr>
<td>13 Feelings of fatness</td>
<td>6</td>
</tr>
<tr>
<td><strong>Weight Concern</strong></td>
<td></td>
</tr>
<tr>
<td>29 Importance of weight</td>
<td>4</td>
</tr>
<tr>
<td>31 Reaction to prescribed weighing</td>
<td>4</td>
</tr>
<tr>
<td>11 preoccupation with shape or weight</td>
<td>4</td>
</tr>
<tr>
<td>32 Dissatisfaction with weight</td>
<td>6</td>
</tr>
<tr>
<td>14 Desire to lose weight</td>
<td>3</td>
</tr>
</tbody>
</table>
5.2.5 Determining Sample size

Determining sample size is ultimately a matter of judgement and experience in evaluating the quality of the information collected against the uses to which it will be put, the particular research method and purposeful sampling strategy employed (Sandelowski, 1995). To achieve a maximum variation of personal experiences it is recommended to include a range of 6 to 50 interviews (Morse, 1994; Sandelowski, 1995; Smith & Osborn, 2008). It is recognised that larger samples may provide more detail and reliable accounts of experiences under investigation but up to the point of data saturation which is the term applied to the point at which no new data emerge (Parahoo, 1997).

5.2.6 Recruitment and sample

The researcher had aimed to recruit a maximum variation sample of 20 each of services users, carers/family members, and health care professionals. However due to recruitment challenges 10 patients with eating disorders, 7 parent/sibling and 18 health care professionals were recruited. All ten participants with eating disorders scored high on the EDEQ (see table 15) and therefore were eligible to take part in the interview. A summary of participant characteristics are presented in tables 17, 18 and 19. Some characteristics are not provided on an individual basis to avoid possible identification of participants. (Please see appendix 9, for researchers’ diary of recruiting participants).

Recruitment of participants

The recruitment procedure was devised in collaboration with the main supervisor and two co-supervisors based at the Universities of Manchester and Liverpool.

Stage 1- Location and contacts

Recruitment was concentrated within Greater Manchester in areas highly populated by South Asians. This was to make sure that the right community was targeted. Well-established mental health and eating disorder websites, for example BEAT and 42nd street were also identified as a way of recruiting particularly Asian females with eating disorders.
Stage 2 – recruitment

Recruitment of all participants was conducted through: Primary care, Specialist services, Voluntary sector, Secondary Care, Third sector, further education, higher education, radio and the internet routes. Service users were recruited from both primary care and specialist services (secondary and tertiary care specialist eating disorders services) as well as through community routes (advertising in third sector agencies) and via the internet. General practitioner surgeries, community mental health projects, colleges and universities were identified within each catchment area (Please see Table 16 below).

Table 16: Places contacted in the Greater Manchester area.

<table>
<thead>
<tr>
<th>Places contacted</th>
<th>GP Practices</th>
<th>Community Projects</th>
<th>Specialist services</th>
<th>Mind Centres (A mental health charity)</th>
<th>Further Education (Colleges)</th>
<th>Higher Education (Universities)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>70</td>
<td>14</td>
<td>8</td>
<td>5</td>
<td>11</td>
<td>4</td>
</tr>
</tbody>
</table>

Recruitment of Participants with an eating disorder and carers/family members

Primary, secondary and specialist practitioners were contacted by letter (see appendix 10) in order to ask them if they would be willing to:

a) Assist in recruitment of service users and carers/family members
b) Consent to be interviewed themselves.

c) Display a poster advertising the study (appendix 11) on their noticeboard.

Health practitioners were asked to send out an information poster (Appendix 11) about the study to potential participants:

a) British South Asian females aged between 16-25, specifically from the Pakistani, Indian and Bangladeshi background, who either self-identify as suffering (or having suffered) from an eating disorder and have not accessed services, or had experience of using services (including in-patient care).

b) Carers/family members of young South Asian women with eating disorders.

This was accompanied by a letter from the practitioner (Appendix 12) with a tear off slip that was sent to the researcher. It also indicated that the person would be
contacted within a week by the health practitioner’s office to ask if they would be interested in being contacted by the researcher. Interested participants were then sent a copy of the relevant information sheet (see Appendices 13 & 14) and consent forms (Appendices 15 & 16) and they were given a minimum of 7 days to decide if they wish to participate.

**Recruitment of Health care practitioners:**

In parallel, health care practitioners who were willing to be interviewed were provided with a copy of the relevant information sheet (appendix 17) and consent form (appendix 18). Professional participants were more readily available to take part in the study, but it was challenging to engage general practitioners.

**Steps taken to increase recruitment through the Voluntary, third sector, further education, higher education, radio and the internet route.**

Voluntary and third sector organisations are not for profit and non-governmental bodies. With a growing number of non-profit organizations focused on social services, the environment, education and other unmet needs throughout society, the non-profit sector is increasingly central to the health and well-being of society. These organisations were contacted, particularly those specialising in providing health and social care to young people and people from a South Asian background, to advertise the study on their noticeboards and websites and invite potential participants (both with eating disorders, and carers/family members) to contact the researcher. Counselling service providers at colleges and universities were also contacted and asked to display/flyers in the appropriate areas of the buildings. The researcher went on radio (BBC, Asian Sound and Sunshine radio) to talk about the research aiming at the Asian listeners. The website Beating Eating Disorders (BEAT) also advertised the study using the same content as for appendix 11 (poster/flyer).
5.3 Ethical considerations

It was important to consider ethical issues for this study, as there were cases of anorexia and bulimia among the Asian females making them vulnerable. The main published guidelines for conducting psychological research are The British Psychological Society (BPS), code of human research ethics (2009). In line with this, the following will discuss the practical process employed to ethical considerations important to the process of this research. The present studies ethical approval was obtained from NRES Committee North West – Greater Manchester. http://www.nres.nhs.uk/contacts/nres-committee-directory/?entryid27=18673.

The following sections highlight the main ethical issues arising from the study and the steps taken to address them.

5.3.1 Informed consent

The researcher devised the recruitment process to give information to all participants about the objectives of the study. Each participant was informed about the topic area through the participant information sheets (Please see appendices 13,14,17). All participants also completed an Informed Consent Sheet (Please see appendices 15,16,18) to take part in the research and to give permission to record the interview and use quotes from it in writing up the research. It was also highlighted that participants could withdraw from the study at any point without providing a reason and they could ask for their interview transcript data to be deleted prior to being incorporated into the thesis.

5.3.2 Protecting participants

The researcher recognised that she had a primary responsibility to protect participants from physical and mental harm during the investigation. The researcher informed all participants that it was their right to disclose as much or as little as they wanted in the interview. She wanted to make sure that participants were as comfortable as possible in telling their story in their own way. The aim was to attempt to address and mitigate the power dynamic between the researcher and the
participant. All participants were informed of their right to refuse any questions, stop or withdraw from the interview at any time without giving reason. Participants were shown copies of their interview transcripts giving them an opportunity to withdraw any statements. None of the participants withdrew any statements and all were happy with their interviews.

Participants were almost entirely interviewed on only one occasion. However, one participant left home after the first interview and wanted to take part in a second interview to talk about her experience of leaving home. All interviews were conducted at a time and place of the participants' choosing: for example all professionals arranged to meet at their place of work, parents and siblings somewhere outside, away from the family home, work place, or the university. Most of the parent/sibling interviews took place in community halls outside community group hours. All females with eating disorders preferred to meet at the researcher’s place of study within the University of Manchester.

As this research dealt with sensitive personal experiences which were to be made public through supervision and dissemination, the potential for disclosing information had to minimised by guaranteeing the anonymity and confidentiality of all the participants involved. If participants became distressed or disclosed issues that required further investigation during participation, the researcher would inform her supervisor, a professor of Primary Care Psychiatry. However this did not happen in the current study.

The researcher particularly ensured that, if a person with an eating disorder had been interviewed and specifically requested that a relative who had also been (by another route of recruitment) approached for participation in the study should NOT be interviewed, their request was respected completely. However this did not happen. Only one of the participants granted the researcher permission to interview her mother as they had a very close relationship. The other females did not because they were in fear of the parents/siblings comments and repercussions from the interview. Most of them commented that their parents were in denial about their illness and did not understand it, therefore did not want them to be aware of the fact that they were
involved in this type of study (Please refer to section 3 and 4 of this thesis for detailed analysis and discussion).

5.3.3. Accountability

The researcher was accountable to participants, because of the interpretations made of their interviews. The researcher was also accountable to the academic institution as the research needed to conform to their standard in order to be approved and therefore all guidelines were followed.

5.3.4. Debriefing

The researcher attempted to ensure that the participant left the interview as far as possible in the same state they entered it. This was achieved by the researcher talking to each participant straight after the interview about how they felt about the interview and by answering any questions in relation to the research. Participants who had become upset during the interview were asked if they wanted to continue with the interview. After the interview, the researcher made sure that the participant was happy with the interview and asked them about how they felt and if they needed to call someone. All participants were happy to talk to the researcher about how they felt after the recorder was switched off because they expressed that it felt good to talk about how they felt and they also felt relieved.

5.3.5 Confidentiality

Although it was emphasised in the Patient Information Sheet that participating in the study was confidential, this was limited if there was a risk to the participant or others and it was made clear to the participants that the research supervisor would inform medical staff in such circumstances. This was also detailed in the consent form.

5.3.6 Data Storage

Personal identifiable information, audio recordings, transcripts and consent forms were stored in a secure location within the University of Manchester only accessible
by the researcher. Data from participants were labelled with the allocated codes only, without personal information, during the transcribing and analysis stages. Electronic information for the purpose of data analysis by the researcher was stored on a Manchester University password protected computer. As the findings will be published all anonymised data (transcripts and data analysis) will be retained in a locked cabinet at the University for a period of ten years. Identifiable data, such as the audio recordings, were erased following transcription.

5.3.7 Cultural sensitivity

The researcher was sensitive to the needs of South Asian participants in terms of making sure they understood the subject area, as the term “eating disorders” does not exist in any of the South Asian languages. They were also informed that the researcher was of South Asian origin and was fluent in Urdu and Punjabi but not Sylheti (Language of people of Bangladeshi origin) but a translator would be provided if needed. All participants were able to communicate in English and were also comfortable in using the occasional Urdu and/or Punjabi word throughout their interview to describe their experiences and feelings, for example ‘rishta’ which is a term used to describe a proposal for an arranged marriage.

5.4 Procedure of interviews

5.4.1 Development of Interview questions

Three sets of semi-structured interview questions (see Appendices 5, 6, &7) developed for the interviews were guided by the exploration of the research aims and questions arising from gaps in existing literature, whilst keeping aspects of the questioning style flexible. This provided a focus for the researcher and participant, but in parallel to this the participant was still able to move relatively freely along other tangents within the interview. The interview schedules were also reviewed and approved by the ethics committee. The interview schedules were used flexibly throughout the interview to allow the exploration of issues that were raised by the participant. Questions generally followed a chronological format and prompts were included depending on the participant’s response.
5.4.2 Interviewing

Interviewing participants with eating disorders
A pilot interview was carried out with a participant who had an eating disorder and this was reviewed by the main supervisor who indicated that the interview schedule was appropriate to proceed with and no further amendments were required. The pilot participant was included in the results of the study.

To orientate the participant to the research area, she was briefly told the main aim of the research that it was about her understanding and experiences of eating disorders, what she considered to have contributed to her disorder, how she coped with it and what her experiences had been in accessing services. She was asked “when do you think you first recognised that you had an eating problem?” this question aimed to explore her personal experiences and perceptions of having an eating disorder. This allowed for further questioning in relation to current perceptions of her condition and how she perceived her families' concerns and reaction to her condition. The second question was, “How did you hear about the service/who referred you to the service? This was to encourage the participant to provide a descriptive overview of the services that she had received and explore her opinions about the strengths and weaknesses of these services. The researcher used further questioning to explore key factors of her experience, including helpful/unhelpful aspects of the treatment and suggestions for improving patient care.

In order to completely characterise the sample, the participants with eating disorders questions were asked based on the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSMIV) criteria. Then were additionally asked to complete Eating Disorder Examination Questionnaire (EDE-Q) before the interview took place (please see appendix 8) which measures weight, shape and eating concerns (Mond et al 2004). The administration of the EDE-Q was used as a screening tool because it is widely used tested and reliable measure to assess eating disorder attitudes and behaviours in community and clinical populations (Rose et al 2013). For the current study EDEQ was administered to make sure that participants were eligible for the research. All the participants tested were eligible (see Table 15).
**Interviewing Parents /sibling**

These participants were briefly told the main aim of the interview, which was to explore their understanding of eating disorders and what it was like living or caring for a family member with an eating disorder. They were initially asked, “What are your views about eating disorders? This question was used to explore their experiences and perceptions about eating disorders and living with or caring for a family member with an eating disorder. This allowed for further questioning in relation to their perception and feelings about their daughter / sister having an eating disorder. The second question was, “How did she/family hear about the service? Who referred her/family?” This was to encourage the family member to provide a descriptive overview of the services they accessed and explore their opinions about these services meeting the needs of their daughter/sister.

**Interviewing Health Care Professionals**

The main aim of the interview was to explore their understanding of eating disorders, and experiences of providing services to South Asian females of Pakistani, Bangladeshi or India ethnicity. After this had been reiterated to participants, they were asked, “How long have you worked in your current post?” This was to explore their experience and perception of working for the mental health services and in particular, providing services to individuals with eating disorders. This allowed for further questioning in relation to their meeting the needs of these South Asian females and the cultural awareness and competence of both staff and service. The second question was “In your opinion what is in place to meet the needs of South Asian female’s experiences eating disorders?” This was to encourage the provider to give a descriptive overview of the services they offered and explore their opinions about the strengths and weaknesses of the service. This allowed for further questioning in relation to raising awareness amongst the South Asian community about their service and about staff getting enough support and training to meet the needs of these clients.

All interviews (please see below tables 17,18 & 19) were conducted at a place and time of the participants’ choice and they all gave their formal written consent and
permission to record the interview. All participants were able to express themselves in English and therefore interviews were conducted in English. However the interviewer was fluent in Urdu, Punjabi and English and participants could express themselves in any of the three languages. Indeed some did use words in the different languages – as they felt comfortable using them knowing that the interviewer was able to understand them. Each participant's characteristics and demographics were tabulated (see Table 17) separately for each group. All participants’ identities were anonymised and given identity numbers. All interviews were transcribed, some by the researcher herself, others by a member of admin staff. The transcriptions were read thoroughly by the researcher to ensure that they were in accordance with the recording and any identifying information was anonymised, also all participants were given pseudonyms.
<table>
<thead>
<tr>
<th>Id Code &amp; Pseudonym</th>
<th>Background</th>
<th>Occupation</th>
<th>Ethnicity</th>
<th>Age (years)</th>
<th>Length of interview</th>
<th>Type of eating disorder</th>
<th>Type of treatment</th>
<th>Total EDEQ Scores -out of a possible 138 (See also Table 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miryam ED 1 Ds650032 Ds650048</td>
<td>A 21 year old university student, at first interview was living at home and was interviewed the second time because she had ran away from home and felt she wanted to share her story.</td>
<td>University Student</td>
<td>Pakistani</td>
<td>21</td>
<td>49min</td>
<td>Anorexia &amp; Bulimia</td>
<td>Counselling</td>
<td>110</td>
</tr>
<tr>
<td>Sabiha ED 2 Ds650037</td>
<td>A 30 year old Bengali single mother with two boys, she had written a reflective piece about her illness which she permitted me to take away and make a copy.</td>
<td>Single Parent /Home maker</td>
<td>Bengali</td>
<td>30</td>
<td>43min</td>
<td>Anorexia &amp; Bulimia</td>
<td>Counselling</td>
<td>116</td>
</tr>
<tr>
<td>Nabila ED 3 Ds650038</td>
<td>A 35 year old married Pakistani female with two children – has been living with in-laws for the most part of her married life.</td>
<td>Teaching assistant</td>
<td>Pakistani</td>
<td>35</td>
<td>55min</td>
<td>Anorexia</td>
<td>Counselling Force fed 2 weeks</td>
<td>77</td>
</tr>
<tr>
<td>Iqra ED 4 Ds650161</td>
<td>A 25 year old Indian medical student, developed eating disorders in competition with her twin sister. Both parents medical doctors and were aware of her illness but she choose not to go for any treatments and tries recover on her own.</td>
<td>Medical student</td>
<td>Indian</td>
<td>25</td>
<td>1h</td>
<td>Anorexia</td>
<td>None</td>
<td>96</td>
</tr>
<tr>
<td>Humerah</td>
<td>A 30 year old Pakistani single mother of two, come from Pakistan to support her</td>
<td>Single parent Home maker</td>
<td>Pakistani</td>
<td>31</td>
<td>29min</td>
<td>Anorexia</td>
<td>None</td>
<td>94</td>
</tr>
<tr>
<td>ID</td>
<td>DS</td>
<td>Diagnosis</td>
<td>Race</td>
<td>Age</td>
<td>Duration</td>
<td>Treatment</td>
<td>Notes</td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>------</td>
<td>-----------</td>
<td>----------</td>
<td>------</td>
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<td>-----------</td>
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<td></td>
</tr>
<tr>
<td>ED 5</td>
<td>Ds650162</td>
<td>husband who was undertaking a PhD in engineering, marriage forced to live with her in-laws in Pakistan.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rukhsana</td>
<td>Community Worker</td>
<td>Bengali</td>
<td>35</td>
<td>25min</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ED 6</td>
<td>Ds650171</td>
<td>A 35 year old has four children, married young due to a promise to dying grandfather. Living with in-laws.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A 35 year old has four children, married young due to a promise to dying grandfather. Living with in-laws.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ED 7</td>
<td>Ds650040</td>
<td>A 26 year old overseas student from an elite background in Pakistan. Living alone in the UK. Does not want to go back home due to family control and pressures.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overseas University student</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ED 8</td>
<td>Ds650043</td>
<td>A 64 year old retired Indian nurse married to an Indian Doctor. Has two daughters and one son. Eldest daughter also developed eating disorders.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired nurse</td>
<td>Indian</td>
<td>64</td>
<td>39min</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ED 9</td>
<td>Ds650044</td>
<td>A 27 year old in full time employment living on her own. Parents divorced when she was 8. Her father remarried. Mother moved to another city.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time employed</td>
<td>Indian</td>
<td>27</td>
<td>32min</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ED 10</td>
<td>Ds650046</td>
<td>An 18 year old college student, very thin and pale. Living with parents and siblings. In denial about having an eating disorder.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>College Student</td>
<td>Pakistani</td>
<td>18</td>
<td>23min</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 18: Parents / sibling characteristics and demographics

<table>
<thead>
<tr>
<th>Id Code</th>
<th>Background</th>
<th>Occupation</th>
<th>Relationship to individual with eating disorder</th>
<th>Length of interview</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nadia Sib/Fam 1 Ds650152</td>
<td>Nadia is a home maker in her mid-thirties a mother of two. Her older sister who is married and living independently suffers from anorexia and bulimia.</td>
<td>Home maker</td>
<td>Sister</td>
<td>39min</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Urooj Sib/Fam 2 Ds650153</td>
<td>Urooj is single in her late thirties living with her mother. Her older sister suffers from Anorexia and Bulimia who is married and living independently.</td>
<td>BME Sexual health worker</td>
<td>Sister</td>
<td>38min</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Kiran Sib/Fam 3 Ds650159</td>
<td>Kiran is married and her younger sister suffers from Anorexia and bulimia she is unmarried and lives with her mother who requires 24 hour care.</td>
<td>Mental health worker</td>
<td>Sister</td>
<td>54min</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Amina Sib/Fam 4 Ds650167</td>
<td>Amina is married and has six children her eldest daughter who is under 16 suffers from an eating disorder.</td>
<td>Part-Time health worker</td>
<td>Mother</td>
<td>42min</td>
<td>Bengali</td>
</tr>
<tr>
<td>Shazia Sib/Fam 5 Ds650172</td>
<td>Shazia is married and has three daughters. Her eldest who is 15 years old has a lot of health problems due to her eating disorder.</td>
<td>Home Maker</td>
<td>Mother</td>
<td>23min</td>
<td>Bengali</td>
</tr>
<tr>
<td>Afshan Sib/Fam 6 Ds650181</td>
<td>Afshan is in her mid-thirties a mother of six, her 18 year old daughter the eldest of the six suffering from Anorexia.</td>
<td>Administrator</td>
<td>Mother</td>
<td>25min</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Moona Sib/Fam 7 Ds650047</td>
<td>Moona is single in her mid-thirties living with parents. Her older sister suffers from Bulimia who also lives with parents.</td>
<td>Health Care assistant</td>
<td>Sister</td>
<td>27min</td>
<td>Bengali</td>
</tr>
</tbody>
</table>
Table 19: Health professional participant characteristics and demographics.

<table>
<thead>
<tr>
<th>Id Code</th>
<th>Background</th>
<th>Job title</th>
<th>Sex</th>
<th>Length of interview</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fozia</td>
<td>Fozia working for a mental health project mainly aimed at young Asian females.</td>
<td>Mental health worker</td>
<td>F</td>
<td>13min</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Prof 1</td>
<td>Ds650141</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shabnam</td>
<td>Shabnam works in a mental health project aimed at the BME community. She has had over 20 years of experience working with young Asian females in relation to their mental health.</td>
<td>Mental Health Advocate</td>
<td>F</td>
<td>39 min</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Prof2</td>
<td>Ds650031</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saddaf</td>
<td>Saddaf is a manager at a MIND centre and has worked with South Asian women for over 25 years.</td>
<td>Mind centre Manager</td>
<td>F</td>
<td>33min</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Prof 3</td>
<td>Ds650033</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kalsoom</td>
<td>Kalsoom has worked as a counsellor for over 20 years and has worked with South Asian females with eating disorders.</td>
<td>Primary Care Trust (PCT) Counsellor</td>
<td>F</td>
<td>1hr</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Prof 4</td>
<td>Ds650143</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gulshan</td>
<td>Gulshan works for a domestic violence project and has worked mainly with South Asian females who have experience abuse by family members in particular parents, husbands and in-laws.</td>
<td>Senior outreach worker (Domestic Violence)</td>
<td>F</td>
<td>46min 1</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Prof 5</td>
<td>Ds650146</td>
<td></td>
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</tr>
<tr>
<td>Hifza</td>
<td>Hifza has worked for many different community project looking at improving the health and well-being of the general population.</td>
<td>Community Health Development Worker</td>
<td>F</td>
<td>57min</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Prof 6</td>
<td>Ds650147</td>
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</tr>
<tr>
<td>Noor</td>
<td>Noor has worked in various health projects in densely populated South Asian communities.</td>
<td>BME recovery worker (Mental Health)</td>
<td>F</td>
<td>22min 26min</td>
<td>Pakistani</td>
</tr>
<tr>
<td>Prof 7</td>
<td>Ds650151 Ds650034</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sue</td>
<td>Sue works as a college student counsellor and has many young Asian</td>
<td>College student counsellor</td>
<td>F</td>
<td>35min</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Prof 8</td>
<td>Ds650147</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Code</td>
<td>Prof</td>
<td>First Name</td>
<td>Last Name</td>
<td>Position</td>
<td>Gender</td>
</tr>
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</tr>
<tr>
<td>Ds650036</td>
<td>9</td>
<td>Joanne</td>
<td></td>
<td>Mental health social worker</td>
<td>F</td>
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<td></td>
</tr>
<tr>
<td>Ds650155</td>
<td>Prof 9</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Joanne</td>
<td></td>
<td>F</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>works as a social worker and has worked with South Asian families and young Asian females.</td>
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</tr>
<tr>
<td>Ds650157</td>
<td>Prof 10</td>
<td>DR Smith</td>
<td></td>
<td>General Practitioner and clinical lead for mental health</td>
<td>M</td>
</tr>
<tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>Ds650158</td>
<td>Prof 11</td>
<td>Lubna</td>
<td></td>
<td>Community Counsellor</td>
<td>F</td>
</tr>
<tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>Ds650166</td>
<td>Prof 12</td>
<td>Fatimah</td>
<td></td>
<td>Youth worker Co-ordinator</td>
<td>F</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ds650039</td>
<td>Prof 13</td>
<td>John</td>
<td></td>
<td>Psychoanalytic Psychotherapist/Clinical Lead</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ds650173</td>
<td>Prof 14</td>
<td>Dr Lakshmi</td>
<td></td>
<td>Lead Consultant Psychiatrist Eating Disorders</td>
<td>F</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Ds650179</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Ds650041</td>
<td>Prof 15</td>
<td>Dr Iqbal</td>
<td></td>
<td>Consultant psychiatrist</td>
<td>M</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Name</td>
<td>Profession</td>
<td>Gender</td>
<td>Duration</td>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>-------------</td>
<td>------------------------------------------</td>
<td>--------</td>
<td>----------</td>
<td>-----------</td>
<td></td>
</tr>
<tr>
<td>Heather</td>
<td>Private Counsellor</td>
<td>F</td>
<td>22 min</td>
<td>Caucasian</td>
<td></td>
</tr>
<tr>
<td>Dr Kahn</td>
<td>Lead General practitioner</td>
<td>M</td>
<td>19 min</td>
<td>Pakistani</td>
<td></td>
</tr>
<tr>
<td>Dr Hamza</td>
<td>General practitioner</td>
<td>M</td>
<td>17 min</td>
<td>Bangali</td>
<td></td>
</tr>
</tbody>
</table>

Heather is a private counsellor and has worked with Asian females mainly suffering from eating disorders.

Dr Kahn is a lead GP and has been involved in many areas of care for South Asian population.

Dr Hamza is a GP in a South Asian populated area for the last 5 years.
5.5 Data management

All interviews were recorded using a digital voice recorder. After the interviews, recordings were stored as audio files on The University of Manchester password protected computer and erased from the recorder. Interviews were then transcribed verbatim using transcription equipment. A numerical code was assigned to each transcript and all personal identifiable information removed.

The researcher used a computerised qualitative data analysis package MaxQDA to store, organise and code the data. MaxQDA is a computer-assisted data analysis software program, which originates from a program called MAX that was developed in the mid-1980s. One of the basic aims of a software tool is to provide an easy to handle tool which allows the researcher to concentrate on their real task: To analyse the data, find the best possible answers to their research questions and to develop theories which help to understand better what is going on in the real world (Kuckartz 2001). The main foundation of MaxQDA is found in the methodological works of Max Weber and Alfred Schutz. They aimed both for methodological controlled construction of typologies. Schutz (1962) indicated that the cognitive process of typification is a fundamental anthropological technique, which enables us to understand our everyday world as well as to conduct scientific inquiries (Schutz 1962:7). Doing qualitative analysis with MaxQDA supports the researcher in their effort to construct empirical types in the process of a case oriented analysis. The overall purpose of the case oriented analysis is to classify and, if necessary, quantify the qualitative data or parts of it (Kuckartz 2001). With this in mind, and in consideration of three sets of data to process, using MaxQDA to analyse was thought to be appropriate. It was hoped this would allow for the emergence of a rich description of the participants experience from which themes could be generated.
5.6 Procedure for analysis

A semantic approach to thematic analysis was used to analyse the data, using six phase process outlines by Braun and Clarke (2006). The emphasis is placed upon the process of moving from individual accounts to shared themes with the aim of exploring the assigned personal meaning of the experience.

**Phase one: Familiarisation with the data**

In familiarising oneself with the data, it is important for the researcher to be immersed in the data in order to establish the “depth and breadth” of the data (Braun and Clarke 2006). This phase began early on in the data collection process, with all interviews being conducted by the researcher. Audio recordings of the interviews were transcribed and the researcher became actively engaged with the data through repeated reading of individual transcripts. Initial comments, thoughts and reflections were noted in the researcher’s diary for later interpretation.

**Phase two: Generating initial codes**

At this stage, each transcript was read with attention to the researcher's initial comments. Comments were made on a line by line basis and coding was carried out by hand on transcripts initially then transferred onto the MaxQDA program. The researcher began by identifying features of the data (codes) that would eventually allow for the identification of repeated patterns within and across the interviews, for each group of participants a thematic map was created (see Appendix 19). Initial coding was broad in that the researcher coded for as many potential themes/patterns as possible and did not limit the number of codes a data extract could have, and used more than one if appropriate. Coding of the data was carried with the aims of the research in mind therefore other forms of control such as self-harm were coded but not included in the finale themes. Coded transcripts were then re-read to ensure all data segments had been included.

**Phase three: Searching for themes**

Here the researcher met and discussed with supervisors how the generated codes might be interpreted and combined into broader themes. This phase ended by collating all the coded data relevant to each theme.
Phase four: Reviewing themes
At this stage the researcher explored connections between codes and emergent themes across each group of participants, rejecting or modifying them. In order to ensure the data extracts accurately represented the themes, the researcher again referred back to the whole data set, leading to some extracts being re-coded and others being discarded. During this stage themes were merged and discarded and sub-themes developed. These themes were reviewed across the data set with the aim of developing a set of themes that provided an accurate representation of the data. (Please see appendix 20 for table of possible themes)

Phase five: defining and naming themes
The main aim at this stage was to identify the essence of the themes, to ensure that there was clarity about what each theme was in all three groups of participants. This involved further analysis of the themes, allowing for refinements and definition with quotes from the data (see Section 3 Chapter 2 – for detailed presentation for final thematic structure of themes).

Phase Six: Producing the report
Excerpts of the text were used to provide examples of the themes. These were further analysed with the research questions in mind. The final stage of the analysis was the production of the report, which is found in Chapters 6 & 7.

In the following results section, the main themes and sub-themes derived from the analysis of the data will be presented using direct quotes from participant’s transcripts.
5.7 Reflexivity

According to Wilkinson (1988) personal reflexivity is important in evaluating qualitative research. This process is carried out by identifying the impact of researcher bias on the study. The interviewer is a British South Asian Pakistani Muslim female, who has experience of working in mental health services aimed at South Asian communities and has set up and managed community mental health projects.

5.7.1 Research Area

The idea for this research evolved over a number of years from observing a friend who was an Asian female experiencing eating disorders, to working with South Asian communities with mental health issues and therefore observing individuals from these communities suffering from abnormal eating habits: not eating enough and yet unable to get support from their family or have the courage to seek treatment. These views are based on the researcher’s own perceptions as a South Asian female growing up in a predominantly South Asian environment in the UK, having a dual cultural identity.

5.7.2 Impact on researcher

The researcher attempted to be as objective as possible as it is understood that within qualitative research, beliefs and assumptions held by the researcher will have an influence throughout the data collection and analysis process. According to Wilkinson (1998), personal reflexivity is important in evaluating qualitative research. This process is carried out by identifying the impact of researcher bias on the study. It is therefore important to remain clear about the ownership of the individual beliefs and assumptions (Elliott et al., 1999). The following section aims to outline some of these perspectives through personal reflexivity with respect to the current research.

During the interviews, the researcher could identify with some of the participants in relation to their difficulties in maintaining a balance between the Asian and Western
culture. The researcher felt at times that she was becoming emotionally involved particularly when interviewing the South Asian females of the research. She sometimes found it difficult to distance herself from particular individuals’ emotional turmoil (see Box 1).

**Box 1: An example of emotional distress of Eating Disorder participants**

For example in one particular case, a 21 year old female, who was initially interviewed, contacted the researcher after a few months in distress, having left home and friends, and staying at a crisis home. She wanted to meet and talk about her feelings. This was discussed with the main supervisor and it was decided that a second interview should be conducted to determine what else she wanted to contribute to the last interview regarding her current experiences and feelings as there was a clear decline in her physical and mental health. A few weeks later, the researcher was contacted again this time from a hospital bed and was informed that she, the interviewee had taken an overdose two nights before because she felt lonely and depressed. She requested the researcher to come and visit her in hospital. The researcher found it very difficult to say no, but knew that she could not get involved any further and did not go and visit her in hospital, but did keep in contact with her by telephone. The individual was discharged from hospital and now remains in a crisis home.

Some participants discussed their parents' negative reactions to their illness and how it made them feel angry, hurt and a sense of guilt in disappointing their families. However in listening to parents and siblings, the researcher found that their families’ perceived negative reactions were probably connected with fear of the unknown due to their lack of understanding of eating disorders. It might also be difficult for the parents to support their daughter in accessing services as this may be against their values, and fear that the mental health state of their daughter could reach the wider community resulting in a negative impact on the whole family.

In order for the researcher to discuss concerns from the study and to encourage reflection upon feelings in relation to the content of the participants’ accounts, throughout the study the researcher sought support from her supervisor who has clinical experience of working with people with eating disorders. It was recognised that there was a need for the researcher and other professionals in this area to develop understanding of the experiences of such individuals in order to focus on raising awareness, diagnosis and treatment.
5.7.3 Recruiting

Recruiting individuals from the South Asian community was very challenging. Despite all the researchers efforts in engaging in services to help recruit potential South Asian participants with eating disorders the researcher felt deflated and frustrated about services providers not responding to her requests. The researcher quickly realised that she could not rely simply on GPs and mental health services to help her recruit and found alternative ways for example talking to community groups, youth groups, advertising on the radio aimed at the South Asian community, displaying research poster in GPs surgeries, community centres, and eating disorder website. Through this, the researcher started to get contacted directly by the potential participants. Recruiting health care professionals was less problematic although GPs that were invited to take part in the study were far more challenging as they did not respond to the requests of the researcher.

5.7.4 Challenge in recruiting potential participants.

The main challenges experienced in recruiting were due to:

a) Gatekeepers

i) The way in which gatekeepers carry out their role can “facilitate, constrain or transform the research process and the production of the data” (Sanghera & Thapapr – Bjorkert, 2008, p.558). In this study practice managers were effectively “gatekeepers” to GPs and the researcher found it almost impossible to communicate directly with GPs about the research. Not one GP responded to the letter sent by the researcher, after a week the researcher followed up with a phone call and their response was a clear “not interested, do not have the time” mainly from the practice manager who, it appeared, had not necessarily consulted with the GP.

ii) Community Groups - Kokanovic et al (2009) argues that issues around power differentials might not be restricted to the relationship between the researcher and the researched; it might also have affected relationships between gatekeepers and potential participants. Community groups invited the researcher to their groups to raise awareness. However; it did not always lead to recruitment. It was difficult to
talk to potential participants alone. It was felt that community workers were being protective of the members of the group. For example a community mental health worker refused the researcher access to an Asian female group member who was diagnosed with an eating disorder on the grounds that she was vulnerable. The potential participant was not even informed of the research. The researcher also found that all of the community groups, including the community workers involved with them had limited awareness of eating disorders and were often shocked to hear that this occurred in young Asian females.

c) Stigma - research has shown evidence of stigma towards individuals affected by eating disorders and there is a reluctance to consider such individuals suitable as friends, partners, employees or tenants (Link & Phelan, 2001). Crisp et al (2000) found that many members of the public believed that individuals with eating disorders should “pull themselves together” and that such individuals “had only themselves to blame”. The researcher found that potential participants and their families feared being stigmatised by their community and peers as being mentally ill. This can result in the family being isolated i.e. not invited to community gatherings, family wedding and parties etc. Potential participants may have been reluctant to get involved because they had a fear of being stigmatised by other members of the community and that their main priority was to recover from the physical symptoms. Rooney et al (2011) found that when recruitment events were hosted in local community centres potential participants may not respond to recruitment calls for fear that members of the wider community would “find out” about their illness. For example he found that older participants with daughters of marriageable age were the most likely to hid their asthma from the community.

d) Subject matter – having talked to many South Asian female community groups aged fifty plus about eating disorders, members discussed their lack of understanding around this topic and were surprised to hear about its prevalence amongst young Asian females. Many argued that it was a Western disease and did not exist in the Asian culture, but could see how it could filter through. Therefore, uptake from Asian females and family members was very slow, due to lack of awareness about eating disorders and difficulty in identifying females with this condition as their presenting problems. Information on eating disorders in the form of leaflets etc. was
not available at all within GP surgeries or community projects within these communities. (Please refer to appendix 9, for detailed diary of recruiting all participants).

e) Confidentiality – Many of the young people as well as some service providers that the researcher contacted, talked about confidentiality issues with the family GP, where often the GP had breached confidentiality and spoken to the parents about any issues that their daughter was facing. Not one participant with eating disorders was referred through the GP surgery, rather they were referred through specialist services for example (Name of centre) Psychotherapy Centre where individual staff took a keen interest in the research and identified potential participants. According to Khan & Ditton (1999) who carried out research on ethnic minority drug use in Glasgow, young Asians believe that a visit to drug agency or doctor would result in their parents and the whole community finding out. They argued that anxiety over confidentiality was not restricted to GPs but included other staff who are from the same community. For example, translators from the same community are not trusted by some patients.

f) Fear – participants experiencing eating disorders may feel fear of rejection by family, friends and the Asian community. Also there was a fear of seeking treatment from professionals because this could get back to their families and there felt apprehension as to whether their needs would meet by these professionals.

Difficulties with recruiting research participants from minority ethnic groups have been reported from a range of research areas, for example social work, nursing research, population health surveys (McLean & Campbell, 2003), public health research (Yancey et al., 2006) and clinical research (Moreno-John et al., 2004). Yet, there is little published literature on measures employed to promote the inclusion of individuals from these groups in qualitative health research (Neufeld et al., 2001).

(This section will be discussed in detail in the Discussion Chapter 7).
4.7.5 Interview questions

The researcher found it useful to use semi-structured questions as it gave a focus but at the same time the participant could also talk about other topics within the interview. The questions were not difficult to construct as they were based on the main aims for each of the three groups of participants. The researcher found it relatively easy to keep the interview running and participants talked easily about their experiences around the topic area.

5.7.6 Interviewing and ethnicity

Interviewing individuals from the same community had its advantages and disadvantages. One advantage was that the researcher has some understanding of the different cultural issues that the South Asian females talked about, for example, lack of awareness about eating disorders among the older South Asian generation and that there is no translation in the South Asian languages for eating disorders. This did come out in the data when talking to the parents group and the researcher had to explain what eating disorders were. The participants were able to use words from South Asian languages during the interview as a way of expressing their feelings with the knowledge that the researcher was able to understand them and they could identify with her. The consequences of the stigma and labelling of sufferers will impact on their marriage prospects, and also carries the risk of them being ‘outcast’ by the Asian community.

The disadvantages of being from the same ethnic community can be two-fold. Firstly, South Asian participants (patients and family/sibling) may have over emphasized their cultural experiences in the hope that the researcher can in some way meet their needs or they may fear that the researcher may be judgmental and breach confidentiality and their issues will be known to the community. Secondly the research was at risk of being contaminated with the researcher's own cultural beliefs and experiences. It was therefore, important to consult with supervisors to ensure that the data included was emergent from the data and not directed by the researcher's own biases. Furthermore, the researcher did not influence the interview process in any way, by responding to the participants in a neutral way, ensuring the
participant was not influenced in any way. Upon data analysis, the researcher felt that all the participants were open and expressed a range of opinions, according to their own experiences.

The researcher hopes that this study will help to draw attention to the needs of South Asian females, who suffer from eating disorders, which will in turn inform clinical knowledge and help develop service provision and treatment strategies. In the following chapters a detailed description of the main themes and sub-themes identified will be presented and discussed with reference to direct quotes from the participants’ transcripts.
5.8 Summary of methodology

This qualitative study was carried out to expand on the epidemiological and qualitative study reviews, as they showed limited research into the prevalence of eating disorders among South Asian females and little to no qualitative research in relation to the views of these women with eating disorders’ experiences and their journey towards recovery. The main aim of this study was to understand and highlight the issues relating to eating disorders and South Asian females though exploring their perceptions and experience of healthcare and the role of family in facilitating or as obstacles to receiving effective care, and understanding the role of family members in the maintenance and recovery of these women. Also, exploring perceptions of health care professionals, including providers of services for eating disorders, about the potential barriers and facilitators to accessing care for this population.

A qualitative semi-structured method was thought to be appropriate means of exploring the subjective experiences of the participants because this does not limit the individual to a control set of answers allowing them flexibility with open ended questions to provide a rich description of their experiences. Thus quantitative methodology was not applied because it is constrictive and applies closed ended questions and looks to test hypothesis and was not considered appropriate for this qualitative study.

There were three groups of participants, South Asian females experiencing eating disorders (service users), parent/sibling and health care professionals. These participants met a list of inclusion and exclusion criteria (see tables 13 & 14) in order to take part in this study. They were recruited from different organisations within the Greater Manchester area as this is highly populated by South Asians (see table 16). Recruitment of family members were through community based projects. Health care professionals were recruited through metal health services.

Before any interviews took place ethical approval was sought and approval was obtained from NRES Committee North West- Greater Manchester. In line with the guidelines for conducting psychological research, The British Psychological Society (BPS), code of human research ethics (2009) main ethical issues were addressed including; informed consent which was given by all of the participants. As the
researcher was accountable to the academic institution the researcher conformed to their standard therefore all guidelines were followed.

The researcher was sensitive to the needs of South Asian participants and they were informed that the researcher was of South Asian origin and fluent in Urdu, Punjabi but not Sylheti but a translator would be provided if needed. Each group of participants were interviewed using different sets of open ended questions (see appendices 12,13 & 14) these were developed with the view of the research aims and questions arisen from the gaps in the literature. In order to completely characterise the sample of Eating Disorder participants they were asked to complete the Eating Disorder Examination Questionnaire (EDE-Q) before the interview took place to assess the participants’ eating disorders attitudes and behaviours (see appendix 15). Only those who scored above the threshold took part in the study (see table 15). Each participant’s characteristics and demographics were tabulated (see tables 17, 18 & 19).

All interviews were recorded and stored on a password protected computer and then erased once transcribed and a code assigned to each transcription. Data analysis package MAXQDA was used to store, organise and code the data using six phase process outlined by Braun & Clarke (2006). Thematic analysis was chosen as a method for analysing the interview transcripts because it both seeks to understand human experience and is a way of organising interview data in relation to specific research questions, identifying repeated patterns of meaning. As the focus of this research was aimed to be broader than that of the individual experience and therefore it was felt the flexible nature of thematic analysis could allow for greater emergence of unanticipated findings and understanding of participants within a wider context, including their family systems.

The researcher has experience of working in mental health services aimed at South Asian communities and has set up and managed community mental health projects. Recruiting from the South Asian community was very challenging due to, gatekeepers, fear of being stigmatised, lack of understanding of the subject matter and fear of breach of confidentiality. The researcher overcame these issues through talking to community groups, youth groups and advertising on local radio, aimed at
South Asian community. This enabled the participant’s to directly ask the researcher questions rather than going through a third person before taking part in the study.

The main advantage of interviewing individuals from the same community as the researcher was that she had some understanding of the cultural issues that were expressed by the participants for example, pressure to conform to the Asian as well and the Western culture. The researcher attempted to be as objective as possible throughout the research, to ensure that the data was not contaminated with her own cultural views supervisors were consulted to make sure data included was what emerged from the participants’ data. It is hoped that this research will help draw attention to the needs of South Asian females suffering from eating disorders, which will inform clinical knowledge and help develop service provision and treatment strategies.
Chapter 6

Results of qualitative Study 3
6.1 Overview

This section presents the themes derived from the analysis of the data from each group of participants. Using Thematic Analysis, three groups of data were analysed together producing two overarching themes with subthemes (summarised in Table 20), these themes were identified because of their importance and relatedness to the research aims. The main aims of the current study are to understand the issues relating to Eating Disorders and South Asian females through:

1. exploring perceptions of British South Asian females who have eating disorders in respect of their experience of health care and their views on the role of family in facilitating or as obstacles to receiving effective care
2. understanding the role of the family members including sibling in the potential maintenance and recovery of the individual suffering from eating disorders
3. exploring perceptions of health care professionals, including providers of services for eating disorders, about potential barriers and facilitators to accessing care for this population.

A detailed description of each main theme and its sub-theme will be presented with reference to direct quotes from participant transcripts. The extracts were selected because they provided the most coherent expression of the themes, while representing the views of the participants. All names and places were removed to protect anonymity with each quotation indicated by the participant who was represented by a pseudonym.

Table 20: Thematic structure of findings

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6.2 Overarching theme 1: Development and maintenance of eating disorders in the context of family and cultural conflict.

The first theme describes the perceptions of Asian females with Eating Disorder, parents/siblings and health care professionals around development and maintenance of eating disorders in the context of family and cultural conflict: Conflict with parents and the Asian culture, particularly the struggle to make own life choices due to parents perceived as being over controlling and making these decisions for them; the pressure to conform to the Asian culture as well as the Western culture; also how Asian females perceive themselves to be treated as a commodity for marriageability and the difficulties faced around marriage. This theme is comprised of three sub-themes: (1) Conflict with family traditions (2) Managing contrasting cultures (3) Commodity – marriageability and marriage.

6.2.1 Conflict with family traditions

Participants talked about the freedom to make their own life choices around education, marriage and social interactions. They perceived this to be difficult because of “over controlling” parents who feared losing their culture and religion due to daughters becoming too Westernised. Participants talked about the pressures and cultural clashes experienced at home particularly due to over controlling parents. Professionals also perceived Asian females with Eating Disorders wanted to take control of their own lives and found this difficult due to parental pressures and high expectations. Participants suffering from eating disorders were perceived by health care professionals and siblings to control their eating as a way of coping with these pressures by health care professionals and siblings.

Control

Parents were perceived as being controlling by females with eating disorders, siblings and health care professionals. Daughters were perceived to be controlled more than their brothers which often resulted in them being dishonest to their parents about where and who they socialised with. Parents were perceived to restrict daughters from, going out to socialize; keeping mobile phones; wearing Western clothes and make up, this could lead to conflict within the family home and daughters controlling their food intake in an attempt to feel they had some control.
The findings suggest that where there is conflict between processes, in this case Asian female with traditional family members, then the Asian female is likely to attempt to establish some form of “internal” control, in terms of controlling her food intake. The consequences of restriction and control by parents resulted in the daughters rebelling against the wishes of the family by controlling what they ate. Although not all participants suffering from ED were clinically diagnosed as having an eating disorder they all talked about controlling their food intake and as a result suffered from some form of health problems for example, not menstruating, severe loss of weight, arthritis, loss and damage to teeth, amongst many others.

“When they [parents] stress me ... I take my bank card to work then maybe after lunch I’ll then go and buy a packet of doughnuts or something and then throw that back up”. Kavita, (ED 9), Employed full-time, 182

“Yeah. No I would say in early...in the middle....early years of my marriage I wasn’t happy. I was very lonely, I did use food to keep control... my bulimia and anorexia got worse.” Shetal, (ED 8), Retired Nurse, 220.

Health professionals, who had experience in working with South Asian females with Eating Disorder, found that their eating disorder was a way of crying out for help as a form of rebellion to the control they experience from parents:

“Where you just go through a point where your parents are stopping you from doing things and not giving you reasons why. When they do they are not...they don’t seem to understand that...the thing that I’ve seen throughout my time is that they’ll stop themselves from eating or they’ll run away from home or they’ll rebel and start fighting with their parents or do you know, do something like that. It’s some sort of crying out for help kind of thing”. Fatimah, (Prof 12), Youth Worker Co-ordinator, 97

Kiren talks about how she understands and recognises why her sister would want to control her eating because she had no control on anything else in her life:

“ So she’s (Sister)...mentally she’s drained. That’s what it is, mentally she’s drained. And she has no control over anything so the food will be her way of control. And that’s it really I think. That’s what it is with her. I understand that; that she needs a control of something in her life ‘cos everyone wants to have control over something” Kiren, (Parent/sibling 3), sister, 257.

Dr Lakshmi described how Asian females treated for eating disorders under her care
perceived themselves to be controlled by their parents and how this led to conflict within the family home, and seemed to precipitate or maintain their eating disorder:

“not having mobile phones, so just kind of not doing the regular kind of things; that isolates the individual within the context of wider, broader society and that leads to tensions within the family and the only form of control in all of that is around diet and so that is how that then reveals itself”. DR Lakshmi, (Prof 14), Lead consultant Psychiatrist – Eating Disorders, 17.

Heather also talked about how Asian female clients with eating disorders under her care would conceal parts of their lives from their parents because of the parent’s constant controlling behaviour towards them:

“but I think people who are intelligent or whatever should really have the right to be able to find out for themselves. I think the parents just didn’t feel that their daughters would go back to them for help and guidance, which I think they would have done but once you start controlling then people start to reject you, to break out and lie. They had no...they didn’t realise how much...how many lies they were being told.” Heather, (Prof 16), Private Counsellor, 220

Rania talks about how she decided to study abroad in order to get away from her controlling parents, as she wanted dissociate herself from them because they did not try to support her and ignored her eating disorder:

“Yeah and maybe they tried in their own way? Not really. They never did. They just immediately disassociated themselves. So then I just say alright, go you know? That’s another reason I was really; I wanted to move away. Because I said there are 7 billion people on earth, if I don’t get along with these people and it took me a long time to think I am not bad...a bad person for not getting along with these people”. Rania, (ED 7, Overseas student, 143.

South Asian females with Eating Disorders in the sample described feeling that they had no control over their lives and wanted to be independent and be able to make their own life choices. They described feeling torn between attempting to emulate the relative independence of their non-Asian peers and feeling controlled by their family. This was described as an internal conflict and the data suggest that when this conflict was experienced, the individual attempted to search for “internal control”,

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something that cannot be governed by others. This internal control is likely to be associated with the development of eating related psychopathology. Miryam describes how she wished to be more independent and not be told what to do by her controlling family.

“just like where I can go, and what I can do.. I was not allowed to go out with friends or go out shopping on my own.. i don’t like having to tell them everything about myself and what I do and what I don’t do ..and I don’t like being controlled as this affects me a lot especially my thoughts and my eating.” Miryam (ED 1) University student - interview 1, 119

For some participants it was too difficult to go against the wishes of their family and they felt pressurised to go along with the choices parents made for them:

“You can’t go against it much. Whatever they…they [parents] choose for you in everything…you just go along with it, I was never allowed to wear makeup or perfume, I feel I have to fill the needs and desires of others.”
Humerah (ED 5) Home Maker, 153

Daughters described being persuaded to be obedient by family members through a range of arguments that made them feel guilty. For example, that they were the eldest daughter and had to set an example to their younger siblings or it was a dying wish of a grandparent. The outcome was agreement with the wishes of the family and feeling unable to disagree. This was often a life changing decision for example, to get married and this lack of control could be perceived to develop and maintain the participant’s eating disorder:

“Well my Granma and my dad and my grandfather, they said… ‘Cos my grandfather, he was really sick, really poorly and he…his last wish was, because I was the eldest granddaughter in the family he wanted me to get married. So he said, ‘we’ve got these proposals for you, would you accept it?’ First I said no and my Granma said, ‘ah look your dada’s not well, your grandfather is not well you know? You should understand that it is a good thing to get you married’. And then I had no choice, I said ok.” Humerah (ED 5) Home Maker, 211.

“I just felt pressurised back then. Like they were just controlling my mind and my sister-in-laws just used to say to me constantly you know; you’ve got to agree to what they [parents] say. And I just saw him one day and it was
all arranged. It was like a proper arranged marriage. I saw him one day and I got married within a week.” Sabiah (ED2) Home Maker 101

Ruksana who suffered from long term Anorexia said she felt upset about getting married at a young age because of her family pressures and would often go home to her mother and cry about this as she felt trapped and could not do anything about it:

“Well sometimes I am upset with my husband; I go to my mum and cry why did you get me married so young?” Ruksana (Prof 6) Community Worker, 288

The data revealed that perceived levels of maternal control can play a significant part in developing and maintaining the individual’s eating disorder, as the individual tries to establish internal control by controlling their food in-take. Mothers were perceived to be particularly controlling over their daughters and closely monitored their everyday activities to ensure that they had very little influence from the Western world.

“...we couldn’t do anything because she [mother] wouldn’t let you, ‘what are people gonna say’? You know that was the normal line that you heard. But that...that...I think that was it; there was just a fear. You know, ‘they’re gonna become westernised’. This is gonna happen, that’s gonna happen. And she just seemed to have double more fear than any other parent. So she, that’s why she did it. It’s that kind of control. But you know the constant don’t do this and don’t do that, where are you, where are you going, why are you five minutes late, why you going five minutes early. And that’s just madness. Now when you think about it...and she still is like that.” Urooj (Parent/sibling 2) sister, 35

“Yeah, there were times where the GP’d be like, I have to speak to her on her own and ask her a few questions. But afterwards I’d get an interrogation and mum was like, ‘is there anything wrong? Tell me what’s wrong’ and, ‘I will know I will fix it for you’ and, ‘just tell me’, and I’d go, ‘oh no, nothing, nothing’. They were just like smothering me all the time. I wish they’d just give me some space just to be me and just to breathe” Miryam (ED1) university student 284

It was mainly perceived to be the mother’s role to make sure the daughter is obedient, and trained to the highest level of being a good future wife. If the daughter made her own decisions the mother could be blamed for not bringing her up properly by the father and members of the community. This in turn made the mother increase
her efforts to control the daughter therefore high levels of pressure and control might be perceived by the daughter.

“not eating mainly because of my mom ..it’s her duty to make sure I stay at home .. I learn how to cook..look after the house ..I do well at Uni ..its all that can’t handle ...a girl who makes her own decisions .they will say that the mother did not teach her anything that’s why the daughter is bad.” Kadijah (ED 10) College Student- Daughter of Afshan, (Parent/sibling 8) mother 207

“...both mum and dad used to get quite upset about it (eating disorder) and they were like, ‘you’re really thin, you really need to put on some weight’. But now that I’m slightly better I think they....and also it’s been six years so they’ve kind of got used to it as well. But my mum; I think it’s come back now (eating disorder) because I’m at that age you know where girls are getting married and things; so she’s like, ‘you need to put on weight if you want to get married’ – this and that so... That’s...I feel that that’s so much pressure as well; this whole getting married thing. And for Asian girls I think there’s a big pressure; you have to be married at a certain age. And I hate that”. Iqra (ED 4) Medical Student, 243

The fathers were also perceived to be controlling towards their daughters particular attention was around not allowing her to mix with individuals who may have different values and ideas from the Asian culture such as socialising freely with the opposite sex, which the fathers fear may result in their daughter becoming too Westernised. Fathers were regarded as the head of the family and participants commented that they gain respect from the community if their family is thought to adhere to Asian cultural values. Participants with Eating Disorders would become dishonest and secretive, hiding information from their parents about their life outside the family home.

“her father was a respected community religious person and he insisted that the children were brought up in that community with very strong values and didn’t want them wearing Western clothes, make-up; used to drop them off at college and school and somebody had to pick them up. Very, very big issues about going out socially and they were...she was brought up in a Western society mixing with people who were allowed to go out and wanted...you know they were encouraged to be academic but going to University they then...she came into contact with other people with very different values and ideas and views and the conflict was just immense and very, very controlling.
She had to hide things and lie...she didn’t have to lie but she did lie”.
Heather (Prof 16) private counsellor, 48

The data revealed that parents started controlling their daughters by introducing greater restrictions at a certain point in their development: Just before puberty they would make greater efforts to orientate their daughters towards more traditional behaviours which could create or exacerbate levels of conflict internally and with the family. Participants described how this change from relative freedom to feeling controlled and trapped could trigger unhealthy eating behaviours.

“I just feel life is getting too controlled by my family as I’m getting older...that’s why I’m like this when it comes to eating.” Kadijah (ED 10) College Student- Daughter of Afshan, (Parent/sibling 8) mother, 211

This suggests the importance of ethnic and cultural factors as determinants of eating problems. Since at this stage they are likely to be seen as a young women who is considered for arrange marriage, parents’ interference with their daughters’ decisions and choices at this stage was in order to prevent them from being too westernised and train them towards married life.

“And the girls [Suffering from Eating Disorders] are finding that difficult in handling, and they start to control their food. They don’t know how to handle it. ‘Cos at one point I worked with these girls in primary school they were free as bird...they were free as a bird. They were able to do anything; take part in any activities and the minute they hit high school there’s a clamp put on them”. You can’t do this; you can’t do that. You’re not allowed to go there; you’re not allowed to go here. And it’s like, ‘why’; ‘don’t ask questions, just do it’. You know girls aren’t going to understand when you aren’t giving them a reason” Fatimah (Prof 12) Youth worker Co-ordinator 77-79.

Parents were described as having planned out the future for daughter (in particular education and marriage) often without consultation with their daughter. Parents’ duty was viewed as ensuring daughter achieved their best up until she is married, in the hope of preventing her from making any mistakes in life, this meant ensuring she settled down as soon as possible.

“The women [South Asian clients suffering from eating disorders] had... they
were sort of repressed I thought. That was the impression I got. They were kept within the family and had it all marked out for them. This is what they were doing; they may be educated but ultimately that what you will be doing”. Heather (Prof 16) Private Counsellor, 184.

Education and Career choices

Sue described how female South Asian students suffering from eating disorders perceived their parents to control which career routes they took often, making them unhappy as they were not able to go against the wishes of her parents:

“And it also shows that the subjects that they (South Asian female Students with eating disorders) students chose often make them unhappy because they are having to do science, they are having to do follow a route of going down that road going to a medical or a pharmaceutical or... because the family wants to, but they don’t want to and that makes them really unhappy but they can’t not do it because of the... if they did then its going against the families wishes and that puts even more pressure on them and that was the problem... That was the reason for some of them with eating disorders.” Sue (Prof 8) College student counsellor, 81.

Those who did make their own choice in education that did not adhere to the parent’s criteria were made to feel ashamed and criticised by the family and the Asian community by openly making negative remarks especially if the chosen career path steered away from medicine and science.

“Even just like grades or degrees or something. To this day I have like trouble saying my degree is...to family members but I really like it and I chose it myself because they’d be like, well it’s not a banking degree or something like a doctorate or something”. Rania (ED 7) overseas university student, 240

Sue also found that most Asian female students talked about the pressure to look in a certain way and the pressure to do well academically:

“You know they would talk about the pressures that they felt at home to do well to succeed, the pressure to look a particular way you know that pressure you know, body image big huge I would say, a big part I would say to look right. They had to look a certain way so pressures of ... academic pressures again that’s linked to the expectations of what they have to do and how well they have to do and so it just feel like they had no way out as it were so the
As a consequence of not being in control of their own lives, not being able to make important life decisions around education and marriage some girls would escape from this pressure through different means for example by agreeing to an arrange marriage, going on to higher education, running away from home, controlling their food in-take otherwise maintaining their eating disorder:

“Yes. But she...I remember her saying to me I've just...I don't care who it is or what it is, I can't...if it means I can get out of this house I’m getting married. So I think that meant, if I can get away from my mother.” Urooj (Parent/sibling) sister 2, 78.

“ But it was clearly a conflict for the patient in some form or another and the conflict within that was the patient had a very difficult position in her family system. There was a number of female siblings and she was sort of bottom of the pecking order and I think operated in this kind of scapegoating role for the family and the arranged marriage was offering her an opportunity to leave the family. Whilst that is kind of a culturally specific to her...I mean lots of...we meet patients who leave home to get away from their parents who are very controlling.” John (Prof 13) Psychotherapist) 107.

Dr Lakshmi describes how some girls agree to an arranged marriage just to escape from the family home in the hope of getting some independence with their spouse. Which is not often the case as they may live with the in-laws who can also be controlling, in terms of looking after their needs i.e. cooking, cleaning, taking them to and from appointments.

“So when we’ve questioned her about whether she feels pressured to do this she is very keen to go ahead with this marriage because it’s a form of escape so the issue of forced marriage is slightly complicated there”. Dr Lakshmi (Prof 14) Lead consultant Psychiatrist – Eating disorders, 47.

Others described how girls suffering from eating disorders ran away from to escape being controlled and this sometimes resulted in being disowned by one or both parents:
“All the time about what...how she wanted to live her life and she ended up actually just leaving; she ended up leaving the family and couldn’t maintain contact with...for a long time didn’t have contact with anybody and then managed to make contact with the sister so she could communicate with her mother. ‘Cos father did actually rule the roost.” Heather (Prof 16) Private Counsellor 50

Heather describes how one patient ran away and was disowned by the father and she never made contact with him:

“she did actually bravely make the step to re-connect with sister and her mum occasionally but didn’t connect with father and with my knowledge of working with her she never made contact again with her father because he disowned her for.” Heather (Prof 16) Private Counsellor,54

Miryam describes how she finally decided to leave home because she just could not cope with her controlling parents. Having left home made her feel very guilty and this worsened her eating disorder but it allowed her to concentrate on getting the right help to get better.

“Yeah I did leave home; I left home in October last year. and I felt like I was... I couldn’t cope at home. Mentally I was just exhausted and I felt like I had to leave home. Since I have left home things are still the same if not a little worse ‘cos the guilt of leaving home has made me a little bit more ill...... And in some ways I’ve been able to focus on getting better but I am still struggling.” Miryam (ED 1) University Student 2nd interview –, 5-11

**Caring for the family**

There were also expectations and pressure to **look after the family**. For example, daughters were expected to take care of sick or disabled family members and obligations to contribute to wider family income, sometimes through additional unpaid employment. These expectations were often at the expense of making choices in their lives around marriage, education and employment. Kiren described how her sister had to give up her job to look after their mother:

“I think a year in her job she actually...she...mum had the stroke so she stopped her job and started looking after mum. That’s it I think. Then from there she’s just been a carer”. Kiran (Parent/sibling 3) sister, 140

This responsibility was viewed as a cause that prompted Eating Disorder females to use their eating to wrest control over their lives back.
“with her eating I think it’s a form of having control somewhere. Because she’s a carer as well; she cares for my mum and she tends to not tell anyone how she is feeling or that she needs help with any…anything or she needs help with mum or…. it’s like I am constantly saying, ‘are you ok?’, ‘Do you want anything?’, ‘Do you want me to look after mum today?’ you know? But it’s a constant, ‘no no it’s alright I’m coping; I’m coping’. But you can usually tell.” Kiran (Parent/sibling) 3 sister, 13

Health care professionals also found that Asian girls with eating disordered perceived high parental expectations and pressure, to carry out chores and also to look after younger siblings/ be a carer for those members of the family who are ill or have special needs.

“expectations of the girl and even if she’s not the eldest in the family, but if she’s eldest female that she is expected on top of all the work that she has to do, that she has to work at home to help her family you know look after younger siblings or in the house do chores so there expected to do a lot more than there brothers.” Sue (Prof 8) College student counsellor, 81

Sue went on to describe two cases as examples:

“In fact two of the girls I worked with they both had a sibling with special needs and they’re the ones that are expected and did look after, you know, they become full time career in a sense for siblings with special needs.” Sue (Prof 8) College Student Counsellor, 81

It can also be perceived as a way of keeping daughters at home away from the outside Western influences:

“It’s more about the fact that they’ve got to be housebound [daughters]; they’ve got to be at home to help cook and do all sorts of things like that. This is what these girls are finding difficult to understand being brought up in Western society”. Fatimah (Prof 12) Youth Worker Co-ordinator 99

**Generational differences**

The level of conflict within relationships often varied depending on which generation parents were from. The first generation of parents were generally perceived as more controlling as they tended to be more isolated when they arrived in the UK and therefore feared losing their culture if the daughter became too westernised. These sets of parents were perceived to be harder to reach as they were less likely to socialise or work outside the South Asian community and less likely to be open with their children and health care agencies. Whereas the second generation
of parents, who had grown up in the UK, were perceived to be less controlling and restrictive towards daughters:

“you’ve got those who are first generation, directly coming from Bangladesh, India, Pakistan, who are living here. And ‘cos they don’t know how to deal with it they don’t know how to help the children deal with it. I think those are the parents are the ones that are struggling. You’ve got those in the second generation whose parents are already here and now they are parents so.” Fatimah (prof 12), Youth Worker Co-ordinator, 262

Perhaps the second generation of Asian Britons are somewhat similar to their Caucasian peers in terms of their personal values. This may lead to enhanced constraints within their family origin, especially for those Asian Britons who considered themselves more modern than their families but who are still living at home. Traditional families were perceived to want to develop as a close knit family in keeping with the South Asian culture but when daughters became educated in Britain schooling system they defined themselves sooner through some of the modern values then are their parents. Thus the family members had disagreements about their daughters’ values and would encourage them to conform to their wishes. Dr Iqbal goes further to describe in percentage ratios what he thought the different generation of Asian parents were and how this may impact on the overall conflict within the home between parents and their children:

“they (parents) would be maybe culturally 75% Pakistani, 25% kind of Western” “Which causes distress but not much”. … “Is relatively easy to deal with. Now their children I think when they are getting to fifteen, sixteen, seventeen they are almost like the other way around now. And that then causes a lot of inter-generational conflict between their parents who are sort of 75% and 25% and their grandparents who are obviously 100% and nought! And I think that pressure is huge” Dr Iqbal (Prof 15), Consultant Psychiatrist, 116 - 122

Urooj talked about how she would often challenge her parents about being controlling and argue that living in another culture would ultimately have an effect on their children and this was something her parents should have thought about before settling in the UK.
“And that was my argument, that; do you think that we're not affected by you know, the British culture? We're just Pakistani? And they...and when I challenged them and sat them down one day and said, 'why did you come to this country?', and they said they never thought...they never thought for a minute when they came that we’d have our children here and we’d live here for the rest of our lives. They said we just thought we’d come over and do some work, get rich and go back home. Which maybe what a lot of families...she said we never ever imagined that we would live our lives here and so there’s...we worry. There’s a fear that you are going to become this, that and the other. And I said well you cannot...you either go back home or just stop doing what you’re doing because you can’t...it’s so unfair on us”. Urooj (Parent/sibling 2) sister, 42

6.2.2 Commodity- Marriageability and Marriage

Closely linked to parents’ expectations of their daughters to be obedient is the importance of marriage and the need for daughters to fulfil the family obligation of getting married. At the time of a daughter’s marriage a dowry is provided which can range from a few thousand or a large amount which has no limit, and would be letting their parents down and not showing appreciation for their hard work to provide for them, so they feel obliged to be obedient and therefore dependent on their parents. Asian female participants perceived themselves to be nurtured and treated as a commodity to ensure best marriageability prospects. This pressure was perceived to be one of the factors in the development and maintenance of their eating disorders, as there was a constant pressure to keep slim and attractive, from family members and the wider Asian community. Siblings and professionals also described how Asian females were nurtured within the home to be conscious of their physical appearance. Parents described being very concerned about their daughters physical appearance and growth, in terms of their height, weight and starting their menstrual cycle on time.

Disappointment

Some parents appeared to be disappointed in having a daughter, as they were seen to be a burden and parents felt they had a duty to ensure their daughters were ready for their married life at an appropriate age, and in order to achieve a good marriage proposal needed to be taught good qualities and be physically attractive. Daughters were expected to be obedient (including accept their parents’ decision), partly in
preparation for future husbands and in-laws. This leads to expectations very early on from the community and other family members upon the girl to be slim and attractive. Participants felt this was a direct mechanism that led to problems with eating:

“I can’t really back that up but a lot of it seemed to come down from the expectation was that they needed to fulfil the family obligation of getting married and what they found was the young eligible’s were also brought up on what the media in this country was turving out. So the expectation is that they...particular girls had to be a certain weight and that was equated to attraction and therefore that’s a drive in that regard. I think there is also lots of -how can I put it? - in terms of reflection of other things I think sometimes the eating disorder is essentially a call for help because it’s as equal to...there may be other things going on”. Dr Khan (prof 17) General Practitioner, 38

Feeling like a burden resulted in poor relationships with parents, in particular mothers.

“mum used to call us, ‘Society’, oh, this is your society. She hated us with a passion. Because we were a burden. That’s how traditional our parents were.” Gulshen (Prof 5) senior outreach worker, 99

“She really is. If nothing else, ok she’s [a daughter] taking up space and she’s eating and taking money for food and just breathing and then she’s gonna get married and then she is gonna leave so there was no pay back to ever having had her around in the first place. She’s...she, that’s it. So one good thing she can do is make a really good marriage.” Rania ( ED 7), overseas student, 98

Parents were expected to provide a dowry for their daughter at the time of their marriage, which can amount to thousands of pounds worth of jewellery, clothes, furniture, a car, even a fully paid off house. Whilst daughters were considered to be a burden, Asian parents appeared to favour sons over daughters as they hoped their sons would look after them in their old age.

“we’re all here and sadly mum and dad passed away. They’re buried here at (name of cemetery). Their idea was for four sisters, three boys; all the girls will get married and we’ll get rid of them, because they are a burden. Sad, traditional our parents were. Boys will grow up and they will look after their parents”. Gulshen (Prof 5) senior outreach worker,93
Pressure to be the perfect commodity

Asian females were perceived by participants in this study to be treated as a commodity by their families in order to gain the best possible marriage for their daughters. Emphasis was on having light skin colour, tall, long healthy hair, slim and a good level of education, these criteria were seen as important for the Asian female to be a complete package for marriage. Participants felt they had to be perfect in every way so that a good arranged marriage could be found for them by their parent; therefore parents trade their thin beautiful and house trained daughters for a good arranged marriage. Participants felt pressurised to excel in education, being a dutiful daughter, household duties, like cooking and be physically attractive for example have a thin body shape. The more perfect the daughters are the easier it is for parents i.e. higher commodity less economic pressure on parents, such as giving a large dowry and chances of a good marriage proposal. Rania went further to explain why daughters are treated as a commodity:

Well, the commodity is a great word because the girl isn’t going to earn anything. She’s pretty much a waste of resources...‘And not all...if she doesn’t fit that commodity then she is not gonna get married and she’s gonna be stuck on everyone’s hands for even longer’. Rania (ED 7) Overseas student,100

Asian females have pressure from parents and the Asian community to be well groomed and attractive from early onset of their lives and are often openly compared to other females from the community the community and by family members in terms of their physical attractiveness and level of education:

“Yes, there was a lot of pressures because the mother-in-laws were putting a lot of pressure, which again from that time and moving on now that is something again that is...’cos the mother-in-laws and the mothers do a lot of interfering and they are putting pressure on the girls to look good and to stay slim. So there’s that pressure that’s common as well. Which is that double pressure.” Hifza (Prof 6), Community Health Development Worker, 75

Iqra explained how this constant comparison between young Asian females occurs more frequently in the Asian community than any other society:

“I think in the Asian community everyone compares you and a lot...a lot more than they do in other societies.” Iqra (ED4), Medical Student, 123
Asian females are pressurised to be slim as this will be seen by potential in-laws as not being greedy, not lazy and a sign of purity.

“It sounds so medieval and it’s so applies like – apart from having the fair skin – dark thing like I think because being thin shows that you are not greedy...you are more...I think it has something to do with being pious as well...priority/purity/vulnerability”. Rania (ED 7), Overseas university student, 70

Young Asian men are perceived to be influenced by the external ideas of the thin female image and have a very definitive idea about what they want in a potential wife and most often being slim and attractive is at the top of the list:

“there is also some about wanting to find an attractive slim wife ..then a larger one even the mothers are becoming more fussy ..i don’t want her because she is fat ..they have these criteria’s ..so girls want look good want to be attracted to the opposite sex so something about dropping their weight”. Fozia (Prof 1) Mental Health Worker, 53-57

Overall parents were concerned about their daughter’s appearance and if they became too thin they did not appear healthy, this then was perceived to affect their marriageability prospects as potential suitors will not approach the family for marriage.

“ And I was fine with that. As she’s grown older she’s obviously shot up; she’s shot up and become very, very slim. Very, very slim. And I am not sure whether it is her diet or whether it’s just the way that she is. The biggest concern for me is the fact that she was delayed in her puberty, in her periods and I was thinking, ‘oh no, I am not going to be a gran mother!’ You always think the worst don’t you?” Afshan (Parent/sibling 6) Mother, 13

Parents wanted their daughters to look their age so that the Asian community and members of the family are aware of their daughters coming of marriageable age. Shazia described how her daughter looked a lot younger than her actual age and she was very frustrated that she did not look grown up:

“She’s 11 but she looks like 7 years old. And my 7 years old girl she look like 3 or 4, 5! She’s really tiny. I don’t know why she’s...same thing. She’s really tiny, I don’t know why she’s...same thing, she’s really...not grown up” Shazia, (Rel 5) Mother, 168
Influence of the Media

Many participants perceived *media pressure* to have an influence on the Asian communities’ idea of what a young Asian female should look like and this how this could also be the reason for the shift from a more voluptuous female figure to now a thinner one:

“Oh yeah, if you look at the Bollywood heroine, she used to be chubby and big busted and big hipped and now she’s this skinny, skinny little thing. I know when I was growing up she was a big busted women with you know a well rounded women and now its totally different. And I think it’s, Bollywood plays a big part in Asian peoples life now the Indian dramas come that come on TV. You got all the Sky TVs and all these channels now. Before you didn’t really get much of that, you didn’t get the Indian films or didn’t get the Indian dramas and now everything’s about the way you look” Fozia (Prof 1), Mental Health Worker, 53-57

“Cos that shaped how people think someone should look like, and that adds to the pressure and it...and it makes like Asian girls want to lose even more weight and look a certain way. Yeh I think that’s just another way of adding to the pressure really”. Iqra (ED 4),Medical Student 128-129

Kalsoom described how Asian women are pressurised and influenced by both the Asian and Western media to be slim and attractive and how having a slimmer figure is now becoming the norm in eastern countries, therefore experiencing double the pressure to be slim compared to their non-Asian peers. This could be seen as another cause for developing and maintaining of the eating disorders as there is constant pressure to keep slim:

*if you look at the bollywood movies very slim attractive beautiful women flat stomach the lot there is something about actually I have got ..you look good right you get that from the Bollywood but then there is that so also have in the Western culture ..being slim .. and the Pakistani saying or you are very smart (bari smart lag ragi hai) – your looking very smart ...Laugh..for them it’s about being smart ..but even that is becoming a more of a norm know in Pakistan where they are sort of if you are fat it’s no go area there is a snobbery coming up now Kalsoom (Prof 4) Counsellor for Primary Care Trust ,45

“And especially the magazines. They’re just always pointing out weight. All the time, don’t you see it? On the covers, she’s put on this much and she’s lost that much. That’s all it is... So it doesn’t help. So you’re always
trying to fight that perfect...being a perfectionist”. Sabia, (ED 2) Home Maker, 251-253.

Urooj describes how mother in-laws are influenced by this media and expect their daughter in- laws to aspire to these images:

“because subconsciously I think those images are going in your head, aren’t they? They’re watching these dramas or they’re watching these beautiful girls and they’re watching these images that they want to see...And that’s what they want to see....And that’s what they’re looking for and their daughter-in- laws and...You know? ‘Co I’ve seen it you know with my own eyes and that’s what...so yeh I suppose Bollywood does have a...and our communities love Bollywood don’t they. And young people...they’re all wonderful and attractive and”’. Urooj, (Parent/sibling 2) Sister, 173-175

“These actresses (Bollywood) were wearing these really tight tops and I remember I looked at them and this was exactly the same period and it was so strong (eating disorder) and I went up to my room and I looked in the mirror and I just thought I would never look like that and it just made me so scared and then later on I found out that both of them had eating disorders. I just thought you know; why were you on TV then”? Rania (ED 7) Over Seas Student, 25.

Iqra talked about how the main pressure to look a certain way comes from the pursuit of an arrange marriage:

“And it shouldn’t be like this. But I think it is like this because; to be honest I think it’s maybe arranged marriages and... It puts a lot of pressure on Asian girls to look a certain way and to be a certain way”. Iqra (ED 4), Medical Student,122

She talked about how people have been to see her sister for a possible arranged marriage and described the comments that were made about the appearance of her sister:

“But she (sister) also wants to get married and she feels like people judge her because when...she thinks...in fact... That’s the other thing; I hate arranged marriages and people coming to see you; like rishta’s (marriage proposals) and things. She said one guy came to see her said that she was too chubby.” Iqra ( ED 4), Medical Student, 384
Moona also talked about the pressure to look a certain way for possible marriage proposals and how this affected her sister to reduce weight over the years resulting in anorexia and bulimia:

“you know if you are ever going to get married they look at is tall, slim, fair girls. And that’s kind of drilled into you and I don’t think that’s… I don’t think that’s…that wasn’t one of the reasons why she’s probably thought about losing weight. I think she’s just generally… we both started together to be honest and we do generally lose good steady weight. But when it came to a point after a year where I kind of yo-yo’d and she kind of went kind of the other way... kind of continued really then you know”... Moona (Parent/sibling 7) sister, 512

Arranging the marriage

So, when the Asian females are of marriageable age parents will inform members of the community and other parents that they are now searching for a suitable match for their daughter and will then proceed to give a list of her positive attributes including level of education and a description of her physical appearance. Generally a member of the community will introduce the two families and they will organise a meeting at the potential bride’s home. When potential in-laws come to meet the girl at her family home they will carry a mental list of what they are looking to see in her for their son.

“I think there added issues for the South Asian communities in regards to family expectations. And if you actually look at something as, looking for a marriage and you’ve got the boys family, ‘oh yes we want the girl to be slim, light skinned a certain way’, they have already got in their head, there nothing about a person’s personality, character, qualifications or you know the why the person is. It more about the way a person looks and I think that adds on that if you are going to be, if you’re going to be looking at a community that has arrange marriages you do have to look a” Fozia (Prof 1) Mental Health Worker, 42-49.

The first meeting often takes place between both sets parents and the girl and only if the parents of the boy approve, a second meeting is set up for the potential groom to come and meet the girl. This happens many times with different sets of potential in-laws over the course of the coming years until both parties are happy for the marriage to take place. Throughout this time there are many rejections and potential suitors are openly critical and will give reasons for their rejection of the marriage.
Mostly it was perceived that the first generation of Asian parents were comfortable in having an arranged marriage, but the second generation of Asian females found this difficult and for this reason parents may force their daughter to get into a marriage because they believe it is the right thing to do, and it generally worked for them:

“We think there is a big pressure in young girls even up to their twenties is that cultural kind of pressure of two cultures. I think it’s more pronounced now than in the first generation because generally the first generation, i.e. people my age or a bit older; they were brought up here but they were much closer to the kind of Asian culture so a lot of them had arranged marriages”. DR Iqbal (Prof 15) Consultant Psychiatrist, 114.

Issues around forced marriage and problems within the marriage were perceived as a possibly precipitating or maintaining of eating disorders among young Asian females. Gulshan described how the idea of going through a forced marriage affects young Asian females:

“The majority of them are forced marriage cases. If they’re not seeing brother and sister being forced, it’s literally their turn....siblings...so the effects they see on their siblings and the effects that...if they going through it, is absolutely...is really traumatic for them. So forced marriages is one of the abuses they go through”. Gulshan, (Prof 5), Senior Outreach Worker, 21

In the first instance many parents were perceived to try and persuade their children to take on a partner from their country of birth. This was an attempt to preserve their culture. This also put pressure on their daughters to travel with parents to their home country and look a certain way in order to find a suitor this was perceived to develop or maintain the daughters ED:

“If some of the parents want to take the kids back home they want their girls to look trendy and slim and light skinned and it’s always a pressure. I think for a girl in any culture really from the day your born to the day you die, this pressures, you know pressures of how your parents want to see you and then once you’re married how your husband wants to see you then there’s the in-laws and then when you have your kids the pressures of the kids really and then it’s like a, you’ve come to a full circle then it’s yours own kids and what you’ve been through and what you don’t what your kids to go through. But
then pressures of the extended family members and the community” Saddaf, (Prof 3), manager for the MIND centre, 79

Shabana described how one of her client’s family wished for her to leave the UK to marry and settle down in America to an individual they had chosen for her:

“That the family said you’re getting married to somebody in America, one of the relatives and she said no, don’t want to go there. She’s the only daughter, so it (eating disorders) stemmed from there”. Shabana, (Prof 2), Mental Health Advocate, 87-88

Parents may try and start the arrange marriage process early on in their daughters life and for many young girls this is too early as they are more interested in developing a career and enjoying their life before settling down to a married life. Saddaf described why some girls are not ready to be married as they want to pursue a career:

“Oh yeah! Yeah especially in the culture you have to be white, light coloured skin, you have to be size zero, tall and slim and that’s a pressure in its self really. But some of the girls they don’t want to get married and they want to have a career as well…. And that’s another pressure for some parents said ‘ah what’s the point of having a career you gonna get married anyway and have kids and be a house wife’. Saddaf, (Prof 3), Manager for the MIND centre, 75

Many Asian females simply go along with their parents’ wishes as they are pressurised from all family members to get married and to be disobedient may lead to family disappointment and stigma within the community. Humerah describes how she would protest to her family about not wanting to marry her fiancée that was chosen for her as she did not feel she had anything in common with him. Her protests were simply dismissed by the family:

“he wasn’t interested in me; I wasn’t interested in him and all the family sat down and they said you have to get married and it stood. I know I’ll get married to him whenever I will. It was that kind of a situation. Even though if I was not happy; whenever it was mentioned I was like, ‘what do you want me to do?! I don’t know him! I don’t want to know him! And they thought,
‘oh no, it’s ok after marriage, you know? You’ll get to know him when the
time is right’. Humerah, (ED 5), Home Maker, 168

Humerah went on to describe how she eventually gave in to her families wishes and
got married. During her marriage she knew he was not the person she wanted to
spend the rest of her life with leaving her very unhappy:

“And we just didn’t really get on from day one. I was really, really unhappy
and I thought is this my life for the next so and so years and I really don’t
want to be with this guy”. Humerah, (ED 5), Home Maker, 108

Once daughters reach marriageable age, as well as getting a good education there are
pressures from parents for them be married and they put emphasis on, for example,
to look healthy but have a slim figure, which the participants perceived as adding
pressure to their controlled lives and maintaining their eating disorder:

“mum and dad used to get quite upset about it and they were like, ‘you’re
really thin, you really need to put on some weight’. But now that I’m slightly
better I think they....and also it’s been six years so they’ve kind of got used to
it as well. But my mum; I think it’s come back now (eating disorder) because
I’m at that age you know where girls are getting married and things; so she’s
like, ‘you need to put on weight if you want to get married’ – this and that
so... That’s...I feel that that’s so much pressure as well; this whole getting
married thing. And for Asian girls I think there’s a big pressure; you have to
be married at a certain age. And I hate that”. Iqra, (ED 4) Medical Student,
243

When an Asian female is at a marriageable age parents together with members of the
community arrange to come and see the young girl at home in order to grade her for
possible marriage proposals. This is often done without the consent of the daughter
and she is expected to look and behave her best. Iqra described how she felt about
people coming to see her at home:

“But it’s just that; people...I think with arranged marriages and...’Cos
marriage is such a big thing in Asian community it’s a huge thing. And I just
hate the way people come to your house and look at you and judge you like
that (for a possible marriage proposal)”. Iqra, (ED 4.) Medical Student, 386
Pressure in married life

There is also pressure from in-laws and partner/husband to be a dutiful and obedient wife / daughter in-law. Married participants talked about being pressured not only to look after their husband and children’s needs but the in-laws too. For many Asian females moving in with the in-laws after marriage is a common practice, this is also where in-laws will control their daughter in-laws’ social diary and also put on pressure to cook, clean and look after the extended family. The unhappiness and distress caused under these circumstances was seen as related to eating problems.

“got married, but I wasn’t of the same caste as them and we...there was quite a lot of problems. And I have seen and I have told the therapist that I’ve seen that I have never been valued and that I have never been good enough because I’ve had to...I’ve had to pose for his family and tell lies and I’ve had this and that and; you know, to be accepted? And I think that has all contributed to my low self-confidence and my eating”. Shetal, (ED 8), retired nurse, 36.

Nabila talked about living with and looking after her sick mother in-law single-handed whilst coping with pregnancy and birth of her daughter and how this built up anger inside her resulting in her eating disorder worsening over time:

“And I think I could have put on a lot of weight if my marriage from day one...if there was no interference. You know if my mind was free and I do everything. Because the first three years of a marriage I looked after my mother-in-law anyway. I got married and I lived with my mother-in-law and my sister-in-law and then my mother-in-law had kidney problems. She had to go on dialysis and I used to have to...whilst being pregnant I used to have to...cook two curries a day; one for her, one for myself and my sister-in-law and my husband...because she didn’t have you know salt and all that in it? And on top of that I was pregnant. And I used to send her...I used to bath her, I used to put her clothes on, send her to dialysis, be...I used to always be at home. You know she used to go three times a week. I never got out in my first four years of marriage. Just constantly looking after my mother-in-law”. Nabila, (ED 3, teacher assistant, 151-152

Sometimes brides are chosen from the parents’ country of birth not only because they will continue with the culture and religion but mostly because the in-laws will have more control on the couple. Joanne talked about how one of her clients
suffering from eating disorders, who came from Pakistan as a bride, was treated by her mother-in-law:

“She (daughter-in-law) had to sleep in the same room as her mother, erm, mother-in-law, on the floor and the mother-in-law would take a stick and poke her and she’d get up.....and the mother–in-law, with all due respect, is the matriarch of the family, and she dominates her. She was only married to get her over to this county to look after his mother that was in a wheelchair”. Joanne (Prof 9) Mental Health Social Worker, 31.

Married Eating Disorder participants talked about the over-whelming control from their in-laws, where they were not permitted to leave the house without consent from the in-laws to ensure that their daughter in-law stayed in their control, and this exacerbated their Eating Disorder.

“But even when I was living with my in-laws and I used to; first of all I used to visit my family very less just because I didn’t have the courage to go and ask my mother-in-law, ‘can I go and visit my dad’? ‘Cos then she’d say, ‘Really? Why do you need to go’? Not that she wants...she doesn’t want me to go but it’s like I have to convince her that I need to go. Whereas I shouldn’t have to. And she’ll say, ‘oh no, you have got two kids, his will happen, that’ will happen, do you know? So whenever I used to go; because they (parents) used to see me after a long, long, long time they could see the difference But I couldn’t see that I had become very thin ”. Humerah, (ED 5), Home Maker, 331-332.

Fatimah described how overseas brides are often made to stay within the extended home and not permitted to leave the house and mostly it is the mother-in-laws who are the controlling force rather than the husband of the bride, she described the life of a Bangladeshi bride:

“...some people that you are more aware of in this community. No relation to me though; who have been married, come from Bangladesh, living here but nobody has ever seen them. And that’s because...not the husbands are like that but that’s because the mother-in-laws like that (controlling)” Fatimah (Prof 12)Youth Worker Co-Ordinator, 280

Most Asian women stay in an unhappy and sometimes abusive marriage to please their parents and the wider Asian community, this was also seen to exacerbate and maintain their eating disorder. These women also stay as they fear their unmarried female siblings will be rejected for marriage proposals if they have a divorcee sister,
as the potential in-laws would fear that the daughters of this household are out of control. Divorce was always seen as the women’s fault because she was perceived to be unable to adjust with her husband and in-laws and therefore she not nurtured well by her mother.

“No, I couldn’t no. I just thought it would be useless; they’ve done what they had to do. Even now if you look at it, my Dad stops me from divorcing him, do you know? Not good. What will people say! Now it’s because you’ve been married ten years. Why would you want a divorce now? Now on top you’ve got two boys” Humerah, (ED 5), Home maker, 183

Participants talked about being unhappy in a marriage due to being controlled by parents and family to marry young and/or to someone they do not want as a life partner, which intensified and maintained the individuals’ eating disorder. Nabila described how her 16 year marriage had been unhappy and it was the reason for her wanting to kill herself or run away from it all:

“For about 16 years it’s been really hard; me marriage. But for them reasons I have wanted to like kill myself and wanna move away or run away. But not for me weight because I’ve had a lot more problems/issues; I’ve had a lot more you know like personal issues rather than you know, weight. If you know where I’m coming from?” Nabila, (ED 3), Teaching Assistant, 133

6.2.3 Managing contrasting cultures and community

As most participants were born in the UK they had grown up in both the Western culture which they may experience through interactions at educational institutions, the work place and the media, and Eastern culture due to parents emigrating from the South Asian continent Parents influenced their children to adhere to their culture through interactions with the Asian community by attending weddings and other festive gatherings. Participants felt pressure from both the Asian culture; to be dependent and Western culture to be independent. The Western culture appears to provide individualism, freedom of choice and with the South Asian culture offering a sense of identity, belonging, sense of community and family. Constantly trying to manage these two contrasting cultures was perceived to be a contributor to the development and maintenance of participant's Eating Disorder.
The Asian community was described as being closely knit and that members take a great interest in each other’s family affairs particularly around marriageability and education. Participants talked about the consequences of not adhering to cultural pressures which seemed to restrict the South Asian participants from speaking about their eating disorder with family members and there was also emphasis on the conflict between the differences in east and west and the difficulties in juggling the two cultures.

“think there was a control issue with….about family dynamics and uh, pressures mostly the conflict between west and east, east and west based, so they were like, constantly juggling these to identities. I think maybe because of that, and that was...there was some presenting issues as well, like depression, feeling not in control. Somehow the food because part of controlling something.” Lubna (Prof 11) Community Counsellor, 32

It seemed that negotiating or merging these two cultures has its challenges. Participants described that whilst some aspects, such as freedom to make important life choices and being able to express yourself, of the Western culture was appealing and attractive, there can often be a conflict with what the South Asian culture values and promotes verses the Western culture.

“So you can’t be the good Asian girl who is going to be obedient to parents, who is going to get married when her parents say and do all that stuff AND be going out, have boyfriends because the two don’t go together.” Dr Iqbal, (Prof 15) Consultant Psychiatrist, 142

Some aspects of the Western culture may not merge well with the South Asian cultural values and the expectations leaving the individual in a difficult position in how to balance this without losing the essence of who they are as individuals. Noor described how young Asian females struggle to fit into the two different cultures:

“ you’ll get a lot of girls like in (Name of town)l who are still playing the dual roles. They’ve got to fit in with their family; they’ve got to fit out with the peer pressures. And I think with an Asian girl it’s difficult ‘cos you’re playing two roles all the time. You know you’ve got to keep your identity at home as a young Asian Muslim girl, and outside as well”. Noor (BME recovery worker) Prof 7, 210
Parents may be scared of change and when they observe a change in their daughters’ behaviour in terms of voicing an opinion for example they will blame it on the Western cultural influences.

“...maybe she did what she [Mother] thought was right. I am sure she knew at some point she knows she’s wrong, but she was scared of that change. She just would not change. Her view was, well I went through it, I survived, what’s wrong with you lot? You lot are doing this because you’re in England. If you were in Pakistan you wouldn’t be, you know, jumping around as much as you are here” Gulshan (Prof 5) senior outreach worker, 99

Sometimes community members showed their disapproval by openly making comments about individuals being too westernized, in the hope that these individuals will not get corrupted any further by the Western culture.

“you’re constantly faced with their values (community), and you’ll get targeted. I get targeted all the time, you know, ‘you’re getting corrupted’, ‘it’s the Western society has messed with your head’, you’ll get all this and, ‘wait ’til you have a daughter and she does this and she does that, then you’ll know’. But their mentality and my mentality is completely different. It’s very, very difficult, very difficult”. Gulshan, (Prof 5), senior outreach worker, 27-28

Mariam also talked about perceiving a lot of pressure from the community and wished she did not have to worry about what they were going to say about her choices in life:

“Yeah I think the community just puts a lot of pressure on individuals and it shouldn’t be like that. It’s nice to be...nice to feel welcome in a community and be open and not having to worry about what others will have to say” Marriyam, (ED1), University Student, 260

It was suggested that Asian females living in Western countries struggle with socio-cultural conflict and having to manage this contributes to the emergence of distress and associated problems, such as depression, anxiety and eating disorders.

“Very, very overpowering. But it is a cultural thing; with all due respect it is [participant’s emphasis] a cultural thing, in my opinion. It seems to be
they’re just not used to having the freedom, they’re not used to having a voice, and therefore their way of dealing with it is to go on anti-depressants. I’ve got two at the moment” Joanne, (Prof 9), Mental Health Social Worker, 17

“And it’s the stress of wanting to do both which causes a lot of anxieties and contributes to mental distress. And then...the way...the expression of that distress comes out through eating disorders, self-harm, depression or whatever else you want to call it. Does that make sense?” Dr Iqbal, (Prof 15), Consultant Psychiatrist), 144

The participants described many ways young girls try to convince their family to grant them some freedom; some agreed to wear the hijab (covering of the head) in order to encourage parents and community to trust them in going out of the house and socializing within the boundaries of the Asian culture (e.g. no alcohol consumption).

“But I see a lot of girls and I think hold on, they’ve got a headscarf on yeh? But then they’re wearing short sleeves; really short sleeves. And then they’ve got tight leggings on underneath with a small frilly little dress! And if the dress was long, up to the knees, that’s fine. But they’ve got this, you know frilly little...and you’re thinking ok, you’re keeping your parents happy and you’re getting your freedom as well. And that’s what’s happening”. Noor, (Prof 7), BME recovery worker, 224

Participants with Eating Disorders also perceived that their non-Asian friends did not understand the restrictions placed on them by their parents and found it difficult to come up with a reason not to socialize with them thus they would often misinform their parents about their social activities.

“So there’s a lot of that pressure because they don’t like saying to their friends, ‘oh my mum’s not going to let me go to pictures tonight’. They have to look for an excuse to get out. Or they’ll say that they’re at their friend’s house but they would have gone to pictures or gone out shopping or gone and met the boyfriend. So they’re still playing hide and seek”. Noor, (Prof 7) BME recovery worker, 204

Participants described how parents would fail to recognise that their daughters are influenced by the Western culture or that they struggle to fit into two cultures, the Asian culture at home and the culture outside of the home thus causing family conflict due to failing to see their daughters struggle:
“So it was a real part of our...I think an ongoing thing for us that there was a constant clash, even more so you know for us there was this, you know a culture at home and a culture outside and your parents didn’t recognise it; My mum more so. You know they were oblivious to this, you go out and you get affected by this culture outside”. Urooj, (Parent/sibling 2), sister, 40

Although the Asian culture was considered an important part in forming an identity through connections with their family and the community, participants talked about how the attitudes of young Asian females were becoming more open to certain aspects of the Western culture, being independent and able to make their own choices in career, marriage and forming their own identity with the mix of Western and the Eastern culture., but this was in conflict with their parents concept of how an Asian female should be:

They’ve still got that added pressure about going abroad and getting married. Yeh? Even though I think 15 years ago we were more open to that. But teenagers now are not open to that. They’ve moved on from that time, they’ve moved on from that century. They’ve seen things happen. They’ve seen friends get married and divorced and stuff. Gulshan , (Prof 5), Senior outreach worker, 204.

The data revealed that attitudes of these Asian women are evolving over time. They want to be self-reliant and make their own path in life rather than follow the one carved out by family members and the community.

And plus they: I think the mentality is changed as well, because there’s...we no longer...and young girls no longer think, ‘oh I’m gonna get married and he’s gonna look after me’. I don’t think people think like that anymore. Not in the circles that I move in or my young nieces. It’s all, ‘I’ve got to look after myself. Okay, I might get married but I’m not going to depend on him’ Uroo, (Parent/sibling 2) Sister, 206.

British South Asian women described wanting to take advantage of both cultures they were exposed to, choosing the best of both Eastern and Western worlds and make a life for themselves:
“sort of East/west best, they pick up the best of both and they get on with their life and they’re focused and they achieve whatever their there to achieve Shabnam (Prof 2) Mental Health Advocate, 333.

So the younger generation has moved on in terms of adapting to the Western culture but their parents, in particular mothers, still remain isolated:

“I think people in this country are more backwards – and I’ve always said this – than what they are in Pakistan, and Bangladesh and India. They’ve just don’t seem to have moved on. Because they are not coming out because of what’s happened now is the young generation have grown up, they coming out but these poor women are still isolated” Hifza, (Prof 6), Community Health Development Worker) 156.

The main reason perceived to be behind parents being controlling and restrictive was their fear of losing their culture and religion:

There a lot of things about Western culture that are not good... “ So I can see why the families are fearful of that. But the women were very intelligent and were capable of working thing out but the families were too fearful . ...To allow them to...and the difference between how the sons and daughters were treated was very marked”. Heather, (Prof 16), Private Counsellor, 198-202

Parents were perceived to feel that their daughter was rejecting them and their culture because they were becoming westernised through having friendships with people from other religions and backgrounds this would often result in parents becoming stricter and more controlling:

“Not to say that it was right or that she would be rejected because...the family saw it as a rejection; that her wanting to develop relationships with people from other religions and backgrounds meant she was rejecting theirs and it wasn’t the case; they just made the controls tighter and they just made it stricter”. Heather (Prof 16), Private Counsellor, 180

There would be a constant conflict between parents and daughters around adopting the Western culture and to conform to their values and beliefs:

“ well because they want to adapt to that (Western culture) and the family is saying no this is not right, you have to conform to our values and beliefs so that is where the conflict is started” Lubna, (Prof 11), Community Counselor, 118

Urooj described how during her years at university she found the Western culture did affect her and when she would return home to her parents she did find herself in a constant battle between the two cultures:
.... they’re going to become too westernised. Yeh, this is gonna happen, that’s gonna happen. Whereas I always challenge it and say well what on earth are you doing here then? And it’s interesting because when I did my degree I went away. I went away and I did my degree in textile design and my thesis was on second generation Asians in Britain. So it was a real part of our...I think an ongoing thing for us that there was a constant clash, even more so you know for us there was this, you know a culture at home and a culture outside and your parents didn’t recognise it: My mum more so. You know they were oblivious to this, you go out and you get affected by this culture outside. Urooj, (Parent/sibling), sister, 40

The Consequences of leaving home

As the struggle of trying to fit into two cultures becomes a constant conflict for the girls at home and an arranged marriage was not an option as a form of escape they believed leaving home could. Some participants described having felt the only course of action was to leave home and go into hiding from the family and community:

“All the time about what...how she [client with ED] wanted to live her life and she ended up actually just leaving; she ended up leaving the family and couldn’t maintain contact with...for a long time didn’t have contact with anybody and then managed to make contact with the sister so she could communicate with her mother”. Heather, (Prof 16), Private Counsellor, 50.

The consequences of this could further exacerbate relations as the parents can become targeted by community members with negative comments and are looked down upon as a failure in raising their daughter. Miryam who eventually left home because of intense pressure and conflict with parents with regards to freedom to socialize about how her family, talked about how she would be treated by the community if she did not attend a family occasion as she was expected to be there:

“When everyone is expected to be there; a family occasion......and I’m not there; I don’t know how...I don’t know what they (parents) are going to say - whether I am at work or really viable is it?” Miryam, (ED 1), University Student, (Interview 2), 252-254.

She went on to talk about feeling guilty about her parents having to cope with negative comments about her by community because she has left home:

“I think it will be really difficult for my parents to deal with; to hear that about their daughter”. Miryam, (ED 1), University Student, Interview 2, 223

The Asian community is perceived to spread news about each other to family and friends so that they can keep up to date about the current affairs of the surrounding
Asian families within the neighbourhood:

“I don’t know. I think they’ve...I’ve no idea. I think; with Asians I think for a start they can’t keep th...they can’t keep a secret! You tell one person it’s all over (name of town) and”...Nabila, (ED 3), Teacher, 192

Shame

Given the emphasis placed on family and community relationships, of the close support is restricted to those seen to be behaving in a way that is consistent with tradition and culture. Individual and families lose support from the community if they were perceived to have brought shame and dishonour to the family and community. This then becomes an issue not just for the family but for the entire community. Participants commented on how people talk when a young Asian female is physically or mentally ill and becomes known throughout the community any damage to reputation becomes difficult to shake off which in turn affects their marriage prospects, making friends and relationships within the community.

“I’ve got a brother that’s a year older than me and I mean that saddens me ‘cos we used to be really close ‘cos we’ve grown up together but...I mean I don’t really want to go into this just because I find it really hurtful but my second brother just don’t want to know me. He told me straight. I’m not allowed to be involved in his life. Yeh. Sorry (crying). Sabiha (ED 2) Home Maker 133.

The community is perceived to blame the parents if their daughter has left home and as parents they are deemed as failures and are often questioned as to why this happened:

“I think it will be difficult for my parents because they blame my parents; like this person’s daughter ran away...Either she was bad or she’s done something wrong, or she’s run off with a boy or....she’s just; yeah she’s just...it’s all on the family”. Miryam, (ED 1), University Student, Interview 2, 221

The family and the young girl are stigmatised by the community as ‘shameful’ and many members of the community begin to disassociate themselves from these family members:

And...I’m not sure really but I know that it would be awkward and uncomfortable. I know that I will get looked at in a different way and...looked down upon and think oh you know; what shame on her family. Miryam, (ED 1), University Student, Interview 2, 233

And I just think that it's unfair. It’s unfair for the people in the community to say things to our parents. Miryam, (ED 1,) University Student, Interview 2, 262
There was fear that families may decide to find their daughter in order to regain their family honour and employ a bounty hunter paid to find her and bring her back to the family home where she may be tortured or forced to get married quickly. This concern is not unfounded. This does occur and, in a small number of cases it can also result in killing their daughter for dishonouring the family name (Ray, 2011).

“Consequences are more severe, again just generally speaking; if it’s a non-Asian she can quite easily just walk out and go home, leave home and live separately. The majority of the South Asian culture you can’t do that, it’s not that easy.... Even though she might be able to run away, but then she’s got all these problems she’s going to face if she does leave. The threats to kill, bounty hunters being paid to find her and bring her back, honour based violence, these honour killings, known as honour based violence. She’s got all of these added effects”. Gulshan, (Prof 5), senior outreach worker, 57

Below is a summary table (table 21) of overarching theme one findings, highlighting five main barriers to accessing services and support in the context of family and cultural conflict development and maintenance of eating disorders

Table 21: Summary table of individual, family and community level barriers to accessing services and support.

<table>
<thead>
<tr>
<th>Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents lack of Knowledge, understanding and recognition of the seriousness of ED</td>
</tr>
<tr>
<td>No language for ED in Urdu, Punjabi, Hindi or Salehti</td>
</tr>
<tr>
<td>Fear of disclosing information</td>
</tr>
<tr>
<td>Generation gap experienced by between parents and daughters</td>
</tr>
<tr>
<td>Fear of bringing shame to the family and stigma of Mental health, arrange marriage impact</td>
</tr>
</tbody>
</table>
6.3 Summary of overarching theme 1

The theme ‘cultural and family conflict’ revealed the importance of the context within which South Asian females live in their experience of eating disorders. A number of factors were evident that impacted upon the development and maintenance of eating disorders. Health Care professionals, siblings and females experiencing eating disorders described not eating was a form of internal control as these female perceived other aspects of their lives out of their control. Parents were perceived to be over controlling and therefore young Asian females were not able to make their own life choices around education, marriage and socialising, hence they were having to manage two contrasting cultures which caused internal and family conflict. This often resulted in conflict within family relationships as the women tried to manage the different expectations and pressures, though often they would concede to demands and expectations, at the expense of their own wishes and this created further internal conflict and distress. Participants talked about Asian females being treated as a ‘commodity’ by family and community members to ensure best marriage prospects. Parents were more concerned about the physical changes of the individual with Eating Disorder and expressed anger as to why their daughter would do this to themselves and were worried about their daughter coming of age and puberty. All married women talked about pressure from the in-laws to be obedient to their demands of looking after them and overall duties of running the house.

All Eating Disorder participants talked about their need to take control over their lives through eating less, self-harming and disconnecting with the family but found this difficult due to feeling a burden whilst recognising the high expectations of parents and the community on them. The consequences of resisting or rebelling was to bring shame to themselves and their family and this could have manifold implications, including isolation, anxiety and depression as well as potential harm from family and community. They themselves work to strike a balance between two contrasting roles (to fit into both the Western and Eastern cultures) with no way to negotiate this with family, peers or wider community, other than dishonest, conceding or escaping. This was particularly marked for, though not exclusive to, daughters of first generation parents. The findings therefore suggest that perceived parental control especially maternal, cultural conflict and/or clash and pressure to
follow traditional values are the main factors contributing to eating disorders among British South Asian females as controlling their eating is a way of coping with these pressures.
6.4 Overarching theme 2: Barriers to accessing treatment

This overarching theme describes the individuals’ experiences of accessing services for treatment and the role of family/community in facilitating or as hindering access to effective care. It also describes the perceptions and experiences of health care professionals of delivering services to South Asian females with Eating Disorder. This theme is comprised of two sub-themes: (1) Exposing the family: bringing shame and failing to please (2) Problems with service provision aimed at South Asian females with Eating Disorder. The themes are drawn across the dataset and presented in turn below, supported by illustrative quotes.

6.4.1 Exposing the Family: fear of family’s reaction and bringing shame

There was pressure on South Asian families to give a good impression to its community particularly of an unmarried female, so she is not stigmatised as having a ‘loose character’ or having any sort of health problems particularly mental health issues. The sense of the family being exposed because their daughter has an eating disorder was discussed in a number of ways. Participants talked about the shame it caused to the parents. Participants also discussed the difficulties in accessing services for the fear of being seen by community members. These influences were identified as causing obstacles in assessing treatment services. Participants reported negative experiences of informing parents about the illness, discussing parents’ lack of support and understanding and parents’ reacting in anger and frustration.

Parents reportedly turned a blind eye to their daughter’s eating disorder, with some participants expressing hurt and longing for their parents to be supportive, and others accepting that their parents could not grasp their eating disorder as a problem of the mind. For this reason parents did not become involved in accessing services or the treatment. :

“My parents never really took me to the doctors about it I think. My mum just thought I was being really selfish and thought she could just shout at me and it would go away really. No, no they never really took me to the doctors”. Kavita (ED 9), Full-time employed, 64
Miryam also described how her parents reacted in anger when they were informed by her teachers about her eating disorder:

“I was seeing a counsellor in college..they (teachers) told my parents that I should come home because I was feeling quite low ..so erm..I came home and (laugh) it was so horrible because I got in trouble and I got shouted at ...and I didn’t understand why I was getting in trouble and shouted at because ..it’s not my fault like ..I they think I was doing it deliberately ..like vomiting and ...so..cos I got a bad reaction from them I didn’t.... I just pushed myself away from them and just kind of basically try and snap out of it kind of”. Miryam (ED 1), University Student, Interview 1, 40

Miryam went on to describe how it would have been easier if she had been able to get support from her parents about her illness and get them involved in her recovery programme but she found this difficult because of her previous experience of them being aggressive with her for making herself ill, by shouting and cursing:

“(Laugh)..erm I suppose the hardest thing is family ..a lot of people have said to me ..why didn’t you just tell your family it would be good to have some support around you cos doing it on your own is too hard...I would like to tell them but ..because of bad ..because of how they reacted in the past that scares me to tell them”. Miryam, (ED 1), University Student, Interview 1,105

She also described how her parents blamed her for her illness and thought she was being a nuisance:

“I suppose in the heat of the moment they said things like, oh it’s your fault, you know why are you being such a nuisance and...you aren’t going to get very far in life”. Miryam, (ED 1), University Student, 2nd Interview 295

Parents considered eating disorders to be self-inflicted they were perceived not to be willing to talk their daughter about her illness but thought by being aggressive and using force this would encourage her to start eating. They were perceived to be more concerned about the appearance of their daughter rather than seeking treatment for any psychological issues that needed to be addressed. Sabiha describes how her father was disgusted with her appearance and the shame she bought on the family within the community. She described how her father would try and force feed her and openly made negative comments:
“I mean they (Parents) weren’t willing to sit and talk to me and see the root cause of why. They just wanted me out of their sight and...They were trying to force feed me and stuff. And like I said my dad used to always make comments like... basically you disgust me; look at the state of you, what...people going to think I don’t feed you ; and what’s wrong with you and... and...I still remember to this day sitting in his car driving round and round and he’s just shouting at me! All the way home just screaming at me! ‘What’s wrong with you’? You know, ‘what do you want me to do’? And it’s all about how I’m affecting them ”. Sabiha, (ED 2), Home Maker, 48

Her parents then refused to allow her to meet with other unmarried female members of the family as she would influence them negatively:

“ And now I’m just seen as the black sheep in our family. So I don’t really get any support from no-one because of...they think I’ve made all my mistakes and you lie in it”. Sabiha, (ED2), Home Maker, 127

As there was a fear of negative reaction from parents, participants were reluctant to disclose their illness to members of the family and health care professionals. These negative consequences restricted the women from speaking out about their eating disorders with family members and seeking help. Thus their health deteriorated with time. In order for their parents to know, they relied on other agencies informing them (e.g. school, GP). The women were very concerned about the consequences of the disclosure and would withhold information from health professionals to prevent disclosure:

“school nurse had told the GP and I had to have an assessment from a psychiatrist and that was the first time I saw a psychiatrist... they asked me loads of questions and erm...I wasn’t honest ...basically I was lying to them ...so I couldn’t get any help .. told them it was like a one off ..and I don’t do it regularly ..but I do. but I didn’t want them to know I didn’t want parents to get more involved ..I would get into more trouble ...so I kind of lied to the psychiatrist and they could only go off with what I was saying so ..they said that I was ok and erm I didn’t need any help so ....erm everyone thought I was ok but I carried on and kind of got worse” Miryam, (ED), University Student, 1st Interview, 40.

Nadia also described how her older sister who suffers from an eating disorder would not discuss her illness with her parents and they would also ignore her physical symptoms in the hope that one day she would recover, she described how her sister
would not talk about her illness to any member of the family in case they reacted negatively:

“…she (sister) never came to us. She never came to my mum. Forget me, why would she come to me? But that’s maybe one of the reasons she never came to my mum; because she was just too…not scared but just like…they’ll probably have an argument and I’ll be just….so there’s no point discussing or talking about it”. Nadia, (Parent/sibling 1), Sister, 216

Kavita’s also talks about her parents ignoring her illness and because of this she has led them to believe that she has now fully recovered whereas in reality her symptoms have worsened, just so that she does not have to try and make her parents understand:

“I think my parents think I am fine now and it’s like quite a big secret and you learn to hide it in a lot of ways”. Kavita, (ED9), Employed Full-Time, 33

Parents were also perceived to avoid finding out more about their daughter’s illness and accessing services because they were embarrassed or ashamed of her illness and did not want the community to be aware of it:

“There is embarrassment; there is a lot of shame. And once, because I guess there is that feeling of being a good mother is about feeding one’s child. There is a lot of power in that and so there is a reluctance often to engage”. Dr Lakshmi, Prof 14, Lead consultant Psychiatrist Eating Disorders, 25

Kalsoom also supported this, saying parents ‘cover up’ their daughter’s illness from the community by avoiding seeking help and reassuring everyone around them that their daughter is in fine health, because they are afraid that their daughter will be stigmatised as an ‘unhealthy candidates for marriage proposals’:

“.i know a couple of girls but I know their mothers are in denial and what has happened to the girls ..where as I can see it and I said look you need to do something and they sort of no no they’re fine there’re fine they dismiss it it’s almost they put purdah (cover) over it because if you talk about that girls got depression they’ve got a problem then marriage problems then nobody will give a rishta (proposal) so no no my daughters fine …they don’t want to look at it” … Kalsoom, Prof 4, (Counsellor for Primary Care) 108
6.4.2 Lack of understanding

Participants also talked about the lack of understanding amongst South Asian families and community members about eating disorders. Family members found it difficult to understand and lacked awareness around eating disorders this was perceived to hinder them from accessing services to help their daughter recover. This could be because they lacked education.

“I feel sorry for parents because of the lack of knowledge, lack of education, lack of being aware of what they’re having to go through which is exactly the same as in any culture, it’s understanding”. Hifza, (Prof 6, Community Health Development Worker), 93

I’ve had bad experiences with them (Parents) in the past ...erm...whilst I was growing up I had anorexia I developed bulimia school were concerned about my health and they had to tell my parents ...which was like...which was really not good because I didn’t want them to know and plus I thought they would shout at me and get angry and erm .. come home because I was feeling quite low ..so erm it was so horrible because I got in trouble and I got shouted at ...and I didn’t understand why! Miryam, (ED 1), University student, 1st Interview, 40.

“They don’t ask; they aren’t interested. They think it’s mundane or they think its ridiculous or failure or something”. Rania, (ED7), Overseas Student, 152

A reason that may explain this difficulty in understanding of eating disorders amongst the Asian community is that there is no term or definition for eating disorders in any of the South Asian languages. Not having a way, in their native language, of describing the experience of Eating Disorder made it difficult for parents to grasp the issues around the development of this illness and talk about it:

“I don’t think they’ll see...I think they understand that, look she’s got a problem and she’s not eating you know? But there is no term in their [parents] book to say what an eating disorder is or whatever”. Moona, (Prof 7), Sister, 68.

Nadia also described that even though her sister had been suffering from eating disorders over a period of time and was under treatment her parents were still unable
to grasp the issues around eating disorders as to how and why it developed and what was maintaining it.

“My parents, they still don’t, you know...eating disorders they do understand that she was down but why she was down or why it started; they still don’t understand that”. Nadia (Parent/sibling 1) sister, 186

Afshan talked about finally realizing that her eighteen year old daughter has an eating disorder after years of thinking that she was acting childish because she was not eating, and it is a phase that she will eventually grow out of:

“I’ve had to stop and actually think about it. And only just now, yes what [daughters name] said but I still didn’t take it; I thought she’s just childish and I didn’t take it that seriously. But now meeting you and actually talking about it has made me think even further and I think that is [developed an eating disorder] what has happened to her”. Afshan, (Parent/sibling 6), mother, 188

Parents that were informed by the school about their daughter having an eating disorder were unable to understand the illness and were confused. Urooj explained how her father was feeling confused when her sisters teachers informed him that his daughter maybe suffering from an eating disorder:

“And the teacher explaining to you know; dad, and dad being...saying I have no idea what this it...it’s just incredible because he doesn’t understand the concept he was quite open minded but it was just a completely; what on earth!! ‘Cos I remember him coming home and saying, ‘I just don’t understand it. Why is she doing this’”? Urooj, (Parent/sibling 2), sister 2, 18

Health care professionals treating South Asian females with Eating Disorder also found Asian parents unable to understand the concept of Eating Disorders compared with Caucasian parents. John described a client’s case, a South Asian female suffering from eating disorders as an example South Asian parents not being able to understand Eating Disorders and highlights why some Asian mothers would find eating disorders difficult to understand compared to a ‘white’ mother:

“But mum found it very difficult to tolerate and I knew that mum found it very difficult to tolerate because it made no sense to her, what her daughter was doing. That wouldn’t be unusual to somebody’s mother who was white” John, (Prof 13), Psychotherapist, 103

Sabiha also explained how her mother just could not understand why she was starving herself:
“But yeh and for her to you know, comprehend this and understand it is beyond her, and she just couldn’t understand. You know, she’d say, ‘why are you starving yourself, why?’” Sabiha, (ED 2), Home Maker, 33

The lack of information on the different types of eating disorders aimed at non-white communities may also be one of the reasons why this community may not be aware and lack understanding around these issues. Raising awareness through appropriate information would help increase this, reduce embarrassment and shame and might increase service uptake.

“But I don’t think there is enough being done out there to raise it. It’s a subject you don’t go onto because it’s like, you know...other things; it just gets brushed under the carpet. There’s not enough literature out there”. Noor, (Prof 7), Mental Health BME recovery Worker, 190

Fozia had been working for many years with the Asian community around issues of mental health and explained that there is a lack of awareness rising of eating disorders by services aimed at this particular community:

“I’ve not seen anything. I have been working in this field for over twelve years, I can’t honestly say that there specific stuff or specific training for the community for parents for young people to engage in and to understand what this is all about. I think a lot more could be done” Fozia (Prof 1) Mental health Worker 91

Information that is available on eating disorders is mostly in English and is perceived to be aimed at the non-Asian community as the research behind it has been on Caucasian participants.

“all of that information is so out there but there isn’t much other than kind of BEAT website and we have a website giving information. But there is absolutely not, and what I hear repeatedly is in the Urdu equivalent of pull your socks up; get your act together. With that kind of feeling around it which is a shame”. Dr Lakshmi, (Prof 14), Lead consultant Psychiatrist Eating Disorders), 49
Confidentiality and Privacy

All groups of participants talked about Asian parents accompanying their daughters to medical appointments, in particular to the GP, even if they are over the age of sixteen. This prevented individuals from talking to their GP openly about their eating disorder as they feared repercussions from their parents:

“Yeah he was but I couldn’t’ really speak to him because I never got a chance to speak to him. My mum always came with me, even into the room so I couldn’t really speak in front of her”. Miryam, (ED 1), University Student, 2nd Interview, 276-278

This also prevents the GP from asking deeper questions and following up on cues, for fear that the parent might disagree with more probing questions and prevent their daughter from coming to see the GP again, which would in things getting worse:

I think the ideal situation would be to get her by herself so then we can probe a bit deeper. Dr Hamza, (Prof 18), General Practitioner, 29

Asian doctors in particular, were perceived to find it difficult to ask the parent to leave the consultation room. They were aware there was a cultural expectation that parents had a right to be present in the consultation and that, as members of the same culture, going against that would violate expectations and potentially damage relationships:

“Ideally I would like to [as the parent to leave the room] but it always seem to be not the right thing to say, I have the sense that it is going to cause more harm than good”. Dr Hamza, (Prof 18), General Practitioner 27

Dr Kahn also talked about the difficulty in diagnosing a young Asian female with eating disorders because she is dressed in a certain way, but also it is difficult to ask further questions as they often attend appointments with parents:

“There is a stereotypical view that some of the young Asian girls dress in a particular way……and maybe it’s not as obvious as most what their body habit is at that moment in time but I also think because of the age group we are dealing with it’s difficult to accept medical care anyway and most of the time they would come in with mum’s or dad’s and naturally I think there was a hesitancy to talk about any issues that they were having”. Dr Khan,(Prof 17),General Practitioner), 20-22

Women who try and access services without the knowledge of parents feared being seen by family or community members accessing any health care services in case it
was reported back to their parents. For example a young Asian female was observed visiting their GP unaccompanied, it could lead to parents feeling ashamed that their daughter may have something to hide – such as unplanned pregnancy:

“it was [GP Surgery] actually 10 minutes from where I live ...and erm that day I felt so anxious I didn’t want to go ..and my friend was like just go ..just go I’ll be there...and, erm, so I told them where I was going ...I might get caught out in case someone see’s me because ....erm people usually tend to report back to my parents ...and I know that they will and I know someone will see me because ...kind of know the people around where I live”. Miryam, (ED),University Student, 1st Interview, 99.

The community was perceived to be so close knit that it would then be difficult to contain the information within the family. Hence the very act of visiting the GP risked potentially shameful information being spread around the entire community:

“I don’t know. I think they’ve...I’ve no idea. I think; with Asians I think for a start they can’t keep th...they can’t keep a secret! You tell one person it’s all over [Name of town] ” Nabila, (ED3),Teaching Assistant),192

In accessing treatments healthcare professionals also talked about Asian females being afraid to access services because they fear being seen by community or family members and therefore avoided treatment by keeping their weight at a certain level - avoiding being admitted to hospital which would then mean family members would establish the true nature of their illness.

This would also involve not being able to take time off work or school, and refusing to take time for treatment, including recommended in patient care.

“whether she may at some point need to be hospitalised, which she didn’t want to be because the family would have necessarily have to know and colleagues at work and all those other things”. Heather, (Prof 16), Private Counsellor, 124

Where services are less visible from parents (e.g. counsellor) within schools, they were more acceptable to the women. However there still remain concerns about whether they would be truly private and that community members (e.g. fellow students) may still become aware disclose that the services were being accessed.
“Interestingly enough I would say some of the Asian young girls they’re not so keen to go to the other agencies however when I say to them they can come into college, the counsellor will come into college then they are more interested but even then its still “where about college will it be?” “Will people see me going to the counsellor?” so there’s still that you know anxiety I would say around sort of being seen or who you know talking to someone”. Sue, (Prof 8), College Counsellor, 36

Miryam went on to describe that because she was unable to talk to her GP about her eating disorder in the presence of her mother she decided to see him without her parents knowledge. But then she feared being seen by members of the community who would inform her parents that she decided to be dishonest to her mother about the reason for her going to the family GP:

“Someone will see me because …kind of know the people around where I live ...so I told my parents …told my mum that I was going to GP practice but it was for research cos at the time I was doing my dissertation and I was doing it on myself and eating disorders but I didn’t tell them that .i told them that I was doing it on mental health on Asian women and erm (laughs) my supervisor had like booked me to talk to someone about the research my mum believed it so erm that was ok...but really I had an assessment for myself...so I had to lie to my mum which wasn’t good but I couldn’t tell her either”. Miryam, (ED1), University Student Interview 2, 99

**Becoming Independent**

If the woman had left home and become independent from her families she found accessing services easier as she did not have to fear being seen and explain the reason for accessing certain health care services. Miryam in her second interview after leaving home talked about how it has become so much easier to access services as she no longer has to fear being seen by her family and community members:

“I feel like I am. I’ve been…I can…I feel like I can access the service really easily because when I was at home I had to hide my whereabouts so even going to the appointment with the doctor or going to see a specialist or some assessment with a therapist I had to hide it. Whereas now I don’t have that worry. I don’t have to think what am I going to say to this person or that person. I can just go to an appointment” Miryam, (ED1), University Student, 2nd Interview, 124-125

Over time the illness was perceived to become a part of a woman’s life, and because of the lack of support from their families they began to cope with it on their own and
began to feel less ashamed and embarrassed about it. Shetal talked about how after 40 years of suffering from eating disorders she had started to talk to her family about it and was no longer concerned about being ashamed of her illness:

“But I don’t think she was aware of my illness, no. Neither are any of my family until the last 10 years or so because to me now it doesn’t matter. It is an illness that I am not ashamed of, you know? It happens; it happens. Why it happens I don’t know but at that time, yes, I thought I was a bad person; I felt bad and...But now I am not...you know I do talk to my sisters about it”. Shetal, (ED8), Retired nurse, 97

Dr Hamza also explains how older Asian females become independent and then they start to take control of their lives and as a result seek treatment more consistently then younger South Asian females with eating disorders:

“I think the older age group of Asian women tend to be better at coming back but I am saying on that age group between the 18 – 40 year old I would say it’s the...the teenagers going on early 20s are the hard ones to really follow up. Whereas the older groups in their 30s I do have quite a few there that do. They seem to be more independent and they seem to be more willing to come for an engagement”. Dr Hamza, (Prof 18), General practitioner, 38.

5.4.3 Problems in service provision for South Asian females experiencing eating disorders

There was much of discussion around recognising problems within service provision aimed at South Asian females particularly around the need for raising awareness amongst and providing training to professionals about South Asian females and eating disorders. Professionals felt they were not always equipped to meet the service needs of this group because they did not fully understand their cultural issues. This was perceived to be made more difficult by a lack of resources in terms of staff shortages, appropriate training and restrictions on time and therapy session allocation for each patient.

Professionals seemed lacking in experience and understanding of South Asian females with eating disorders and talked about wanting training to improve their services. Healthcare professionals largely described having limited understanding of the issues and having received no training.
“I think the awareness (of eating disorders) amongst health professionals is limited”. Dr Khan (Prof 17), General Practitioner, 22

They felt that having a greater understanding of the issues for this community would help them identify and manage the problems more promptly and effectively.

“Because I don’t know much about it, I don’t know what I am looking for. I don’t know what the issues are, I don’t know what the effects are, and I don’t know what the consequences are. So therefore I can’t handle something that I have no knowledge of. But if I have that knowledge I will then be looking at issues in a different way and asking prompting questions. And then will be able to deal with the issue a lot quicker. I am not dealing with it because I don’t have that knowledge. But yes, definitely if I had the knowledge I would certainly do a lot more around the eating patterns that they have” Gulshan, (Prof 5), Senior outreach worker, 31

Healthcare professionals admitted they prioritised other problems because of this lack of knowledge around Eating Disorders and South Asian females, despite being aware of its impact on patients’ well-being. Lacking confidence and understanding in Eating Disorder problems for South Asian women meant they were reluctant to ask about the problems or respond when women revealed symptoms of Eating Disorders.

“The majority of women that come to Women’s Aid for support have disclosed that due to the abuse that they are going through, one of the issues that they do face is their eating habits. We don’t have...number one we don’t have the capacity, we don’t have the knowledge and we never go deep into that particular issue, ‘cos there are other issues that are a lot more important. For example, keeping her alive. I can see it’s having an impact on them and their mental health. How serious it is with them, I really don’t know to be honest I don’t know what to be asking them, around their eating habits or eating orders. I wouldn’t know what to ask.” Gulshan, (Prof 5), Senior Outreach Worker, 15

This lack of knowledge and awareness was reflected in women’s experiences when they had sought support from healthcare professionals.

“But I have found the GPs are not very helpful. They themselves don’t know much about eating disorders you know”? Shetal,( ED 8), Retired Nurse, 233

For many participants the focus of discussion was on their experiences and perceptions of GPs being unsupportive or having a lack of understanding of the issues around Asian females and Eating Disorders. There was shared understanding
about what a particular GPs approach would be, which is likely to further hinder a woman accessing help and disclosing problems:

“I don’t know if you’ve heard but the doctor on [name of road]; he’s blatantly rude in your face. He’ll prescribe paracetamol and that’s it, sends her off. And there’re so many complaints I can’t tell you how many people have walked into our office and said, ‘oh you know that [GP Name], he’s such a so and so’, and she’s sworn at him because you know he’s just...he’s not doing what he’s supposed to be doing”. Kiran, (Parent/sibling 3,) sister, 305

Afshan blamed her GP for not taking her seriously and not recognising that her daughter suffered from anorexia:

“She doesn’t see it as a problem but perhaps if a doctor had said to her, look this is what I want to send you to, she would have taken it more seriously which is why they are at fault in terms of not recognising that” .Afshan, (Parent/sibling 6), Mother, 176

Others were frustrated with their GP because they were not being referred to appropriate services quickly enough and then were being put on long waiting lists:

“I have seen my GP numerous times erm the last time I went to see my GP was in January for an assessment I have been referred but I am still on a waiting list which is kind of frustrating because I was getting help.. I would like somebody to be there ..like some support..some professional help ..because kind of struggling on my own and ..and just being put a waiting list so I can’t really do much but wait” Miryam, (ED 1), University Student, 1st Interview, 17

Most participants felt their GPs were unhelpful and they were given false reassurance. In particular mothers were concerned over their GPs lack of support and communication when they attended with their daughter suffering from Eating Disorders; often coming away without being weighed or a blood test and being reassured that their daughter was Ok and there was ‘nothing for her to worry about’:

“I am thinking...I think I should try you know blood test anything. Doctor said they (Daughter) are fine, don’t worry. That’s why I am fed up. There’s no point to go to the doctor”. Shazia, (Parent/sibling 5), mother, 282.

Dr Hamza agreed that there was a need for further training for GPs and this would prevent further delays in providing the right services:
“I think the main thing for me is...from our discussion just now has triggered a learning need. And that’s good, that is the benefit of it and I might even log this as a learning need. Because it’s something that is not talked about. And you know obviously I don’t know the facts and figures behind it but if there is something that is significant and it is being brushed under the carpet and not being addressed then it would be quite an important area because if we can get the services in right we can prevent a lot of complications before it happens”. Dr Hamza, (Prof 18), General Practitioner, 135-141

Dr Hamza admitted that they only weighed a patient if they complained about their appetite and thought that it was important to carry out an initial assessment:

“We don’t weigh them [patient] which is an important thing. The only time we would consider weighing them is if we think there may be an underlying medical condition so if they themselves mention weight loss and tiredness or anxiety then we thinking like an eating problem – maybe thyroid or is there underlying anaemia with an underlying cause for it? But if they come in and they have no other systems question...when we are asking basic systems questions and they don’t seem to answer then we can’t...that is a biological symptom but yeah you are right it’s...there is a potential there”... Dr Hamza, (Prof 18), General Practitioner, 44

He went on to say his surgery could start to record BMI as part of an initial assessment which might help to pick up the signs of eating disorders:

“Maybe BMI could be checked as part of a routine check. I mean when people are tired all the time it’s easier for us to do a BMI cos then I can use that as an excuse so if they are tired all the time with depression I can go down that route. But maybe it could change our practices”. Dr Hamza, (Prof 18), General Practitioner, 95

Health professionals highlighted that most health check tools have been developed using research carried out on the Caucasian population therefore these may not be appropriate for the Asian population. They therefore cannot always pick up the signs and give an accurate diagnosis:

“Having said that the BMI itself is more prudent for a Caucasian population. We know in Asians that lines are going to have to be redrawn in a lot of health perimeters not just BMI because it’s not appropriate, BMI itself, the
thresholds are being redefined because the South Asian health is different”. Dr Khan, (Prof 17), General Practitioner, 53

Breach of Confidentiality

It was perceived that the older generation of Asian GPs work on building relationships with their patients ‘as a family’ rather than treating each patient as an individual. They feel this is necessary as these GPs often have links to the family back in their home country and therefore feel it’s their duty to make sure their patients’ daughters are adhering to cultural expectations and sometimes this can result in breach of confidentiality.

“I think Asian GPs work in a slightly different way. I think they work much more on relationships, especially with the elder generation, because they are from the same background you see so a lot of the Asian GPs who are from Pakistan, India, Bangladesh...they are very good for the Pakistani, Indian, Bangladesh Patients. I don’t think they are necessarily best for people who have grown up here because there is a fundamental, cultural misunderstanding”. Dr Iqbal, (Prof 15), Consultant Psychiatrist, 205

“he was Asian and the family doctor.. I knew he would have told my mom about what i tell him ..because he knows my father back in Pakistan ...I just did not want to take the risk”. Kadijah, (ED 10), College Student, 119.

He went on to say that it is common practice for Asian doctors to talk to other Asian doctors about their patients’ health and other family issues referring them by their real names:

“when groups of GPs gather And they will be there talking about patients as if they are just member of the community. There is a confidentiality issue – it’s openly spoken about...he’s this persons relative and he’s got this problem or...his daughter has done this or...that kind of...yes I have heard that. And I have said so as well, I’ve said I think that is wrong, you shouldn’t really be talking like that because it is that relationship”. Dr Iqbal, (Prof 15), Consultant Psychiatrist) 215

Health care professionals reported that South Asian females were reluctant to talk to their South Asian GPs about personal issues affecting their health due to fear of breach of confidentiality.
“some of the girls that I have had contact with have told me that in two different cases that you know they wouldn’t go and see there GP because there would be no point because the GP would tell their families and so they didn’t want to go and speak to the GP…. Or they would go and speak to them but not about the actual issue, if it’s about eating. It’s a sense of my mum and dad are going to find out about that and I can’t cope with that pressure and then another GP sort of basically said to one of the clients oh yes yes yes I know your family that’s right, I think you should be speaking to them rather than speaking to me”. Sue, (Prof 8), College Counsellor, 58

This was not particular to Eating Disorder problems, but to all aspects of healthcare:

“Well some of the GPs; I’ve had one case where the GP...a young woman went to the GP, right? She wanted pills [contraceptive pill] and the GP kind of mentioned it to her mum. So I got the young girl to change the doctor right? But she got a lot of flack and it was just that the girl was going to go abroad to get married and she wouldn’t...she didn’t want to get married in the first place”. Noor, (Prof 7), Mental health BME Recovery Worker, 52-56

Mental health professionals were also wary of sharing information with their South Asian GP colleagues as they lacked confidence that information would be treated confidentially and were concerned about the risks to the woman if there were leaks in the system.

“There’s examples where the women has sort of said they’ve got problems and they have come to the service and then you have written to the GP because you have got concerns and it gets back to the husband...that they have been in ..so ..there’s been loads of different instances” Kalsoom (Prof 4) Counsellor for the PCT 59

This can lead to problematic relationships within healthcare teams and impact upon the care and coordination of services.

“..I have become very tactful now on how I have address Asian Gp’s more so then the white GP’s and the reason being that what happens is that when I’ve approached and I’ve sort of said you’re out of order for doing da da da...what happens is that you realise that the GP referrals drop ...right so that’s happened I learnt that very early on in my career of working and it actually has made me more biased when it comes to Asian GPs ..but the problem is rife ..and it’s not something that is talked about and gets brushed under erm but I’ve learnt by me ranting and raving and pointing things out
doesn’t help that situation .you have to become more political in how you deal with it”. Kalsoom, (Prof 4), Counsellor for the PCT, 59

**Diagnosis and referral to specialist services**

There were several different reasons why GPs delay or do not refer young Asian girls to specialist services for eating disorders: GPs lacked understanding about South Asian females and eating disorders; the GP tend to concentrate on the somatic issues rather than psychological; older Asian GPs believed referring a young female would create disruption within the family; some GPs did not realise that eating disorders could exist among the South Asian community and therefore did not look for the signs.

“GP’s are **gate keepers** they are also very powerful in actually stopping people coming through or putting people through..or the fact that they are not understanding ..there are different reasons why GP’s weren’t referring one was for the fact that they didn’t pick up that they needed the service ...secondly well how can they help an Asian person right so there was that but then there was the power thing as well especially when there was a female going to a male so there’ll be other things that would be going on and ... so there is something about ....despite the fact that you might have a GP the other thing which was said to may face that by referring them (Asian women) it opens other things it can cause disruption in the family ...so .better to keep the women in their place” Kalsoom, (Prof 4), Counsellor for PCT, 59

Dr Smith highlighted that generally GP’s concentrate on one issue presented by the patient and somatic rather than psychological and also experienced that mental health services concentrate on the psychosis rather than the affective disorder:

“I’ve got some evidence that if you give two problems to a GP they concentrate on one. And if there is one that is somatic and one that is psychological, they will concentrate on the somatic. If a person has two psychological problems I know that if they have psychosis affective disorder they will concentrate on the psychosis and neglect the affective disorder. The whole of the Mental Health Services do that”. Dr Smith, (Prof 10), General Practitioner and clinical lead for mental health) 8

Dr Smith went on further to explain why eating disorders are not seen by GPs as life threatening and therefore they might not see it as a priority:

“*Because what General Practice is about is really about danger. That our job is associated with, partly with rescuing people, but the thing that GPs are*
South Asian patients were less likely to talk about their psychological issues with their GP and most described their somatic symptoms because they did not want to be stigmatised with mental illness or did not know how to describe their distress. This resulted in patients not being diagnosed for psychological stress instead given a prescription for a physical symptom. Kalsoom also talked about GPs often diagnosing the presenting problem and sending Asian patients away with a prescription rather than addressing the psychological issue:

“GP’s have ..and then they have only less time to see somebody so they won’t look at that ..they will just look at the presented problem which the Asian client would present them with, because they don’t want to talk about it or they don’t know how to .. give them a prescription and send them on their way. They won’t look at the psychological background”. Kalsoom, (Prof 4), Counsellor for the PCT),77

Since many were not referred by their GP early on in their eating disorder, over time they become very ill and it was only when they reached a crisis point were they referred to an appropriate service:

“when a client comes and she got an eating ..and it’s very visible a lot of the time the GPs won’t address it clients ..you find a lot of Asian clients end up coming to crises point before they enter into services”. Kalsoom, (Prof 4), Counsellor for the PCT, 59

So there seems to be a need to open alternative gateways to general practice that are clearly signposted, in order for patients to quickly access appropriate services.

“I felt services needed more education then the people ..because services in order for people to access services there have to be the right gateways..have to be there and like you know like practice managers ..so it’s finding another gateway apart from the GP”. Kalsoom, (Prof4), PCT Counsellor, 166

**Cultural Issue**

There was some discussion about the importance of knowledge around cultural issues of clients so that their psychological issues can be addressed appropriately.
Hifza talked about how non-Asian staff are unable to relate to the Asian cultural issues that these young women experience throughout their upbringing and therefore they are unable to support them beyond a certain stage:

“white person that’s working there, will not have that skill and ability to work with that Asian person. So it’s that misunderstanding. And again what happens is the professionals don’t understand the diet, the food, the culture, the upbringing and then again the caste systems. And I think that is something you would have to be quite knowledgeable to understand that”. Hifza, (Prof 6), Community Health Development Worker, 77

Due to lack of knowledge around South Asian culture amongst the Non-Asian professionals, and because South Asian members of staff feel obligated and sometimes expected by other work colleagues to going over and above the line of duty. Hifza talked about translating for Asian members of the community in her job even though this is not in her job description or is being compensated for this service:

“I don’t get paid for it, don’t even get recognised. It’s just like, it’s part and parcel of your job. And it needs to be done, and yes, you’ve got that skill and well done you; pat on the back, just got to do more of it. Even to a stage now if I’m sat in a room with a person who doesn’t speak I’ve been told, well if you...you need to use your translation skills”. Hifza, (Prof 6), Community Health Development Worker, 115

Kalsoom also discussed the importance of the health care provider in understanding the importance of the cultural issues of their patients, as this would help them to assess the issues and help the patient to their road to recovery:

“with some clients you need to understand the culture ..to be able to work with that individual because depending on where they have been raised ..what there background is ..where there family came from .when that came into this country ..what was the culture ..and the mind sets of where they came from how educated are they ..all these things play a big factor”. Kalsoom, (Prof 4), Counsellor for PCT, 47

Kalsoom went on to talk about how over a long period of time she has come across cases where Asian females have not been assessed correctly and this has resulted in
their deterioration because even specialists were not able to identify the issue behind their illness:

“if you get the assessment right then you can work with the problem working with Asian girls who have had five, six, seven, eight psychiatric assessments and they still not got to the bottom of the problem that’s psychiatric that’s not screening at a primary care level because it’s got that far ….and they have not been understood”. Kalsoom, (Prof 4), Counsellor for PCT, 87

Non-Asian health care professionals acknowledged that they did not have the cultural background to understand the issues of South Asian females with eating disorders and were, concerned about offending their Asian clients by clumsy language or exposing their ignorance by the questions they asked. This could inhibit them in asking questions and exploring what were sensitive topics. This made working with South Asian patients challenging:

“And you know you feel they are not part of our culture; I was constantly concerned I was being offensive or getting something wrong or not asking appropriate questions. I think your own limitations...become quite marked really ... So I think it was difficult; I found it challenging because I didn’t know enough about their...society that they’d grown up in or the values or...I kind of knew the conflicts that must be going on but it wasn’t really fully...familiar with them really”. Heather, (Prof 16), Private Counsellor, 92-104

However, not coming from the same background was not entirely a barrier, as health care professionals working with this community learnt over time through gaining experience of treating these patients to ask the right questions.

“They taught me a lot, which is good. Clients teach you an awful lot about their family and about their society...I think I was shocked by how I kind of had a vague awareness from what I had learned and read that people were caught in this cross culture... Of Western values and their family values, which certainly in my two cases were very strict religious families and the girls were expected to adhere to that. Marry within the community, and not even really socialise that much out of it. Go to college, go home, so the two parallel lives were much more marked than I had realised. And that is such a difficult thing to manage”. Heather, ( prof 16), Private Counsellor, 112-178

Many Asian women are mostly covered from head to toe and it can be difficult for GPs to identify an eating disorder as a presenting illness.

“that’s part of it. And of course, when Asian lady’s come and see me, they are usually well wrapped up Because they were so modest, especially with
their husband being there, are modest anyway. It was very difficult”. Dr Smith (Prof 10), General Practitioner and clinical lead for mental health, 69-73

Training

Eating disorder awareness training is not included for new doctors and has only recently been included for psychiatrists. This lack of awareness amongst professional impacts on the wider community:

“I mean it has taken this long for there to start to be an awareness amongst primary health care professionals so GPs it isn’t even included on the training for new doctors. It isn’t included on Psychiatrist training up until recently. It tends to be something that is optional so it is completely understandable that the knowledge just isn’t there. So if that is the case amongst professionals then of course it...amongst the wider public it is really not there and what is a shame is that”. Dr Lakshmi, (Prof 14), Lead Consultant Psychiatrist Eating Disorders, 47

Dr Hamza also suggested that raising awareness amongst GP’s would be a good thing as it would allow them to look out for the signs and carry out appropriate initial assessments:

“I think it would be good for us to get training. I think it’s a niche area in terms of our vision of what is required for general practice but you know obviously you are doing the research and it seems a big area so it could be that more awareness is made – what are the cardinal symptoms to look out for, what are the signs to look out for? Maybe about...if there is evidence there about the BMI being part of a depression initial assessment”. Dr Hamza, (Prof 18), General Practitioner), 91

Fozia talked about how services might be improved for South Asian females with eating disorders if there was appropriate training provided:

“Mental health Professionals need to ongoing training in the needs of Asian females with ED. But I can honestly say if staff were trained and they were then delivering this training to the community of course people would be coming forward. They would know who to access they would know how to get to you for help. At the moment because nobody knows what’s out there and what’s port is available. Where they going to go? I think we can do a lot more about it”. Fozia (Prof 1), Mental Health Worker, 91
Afshan also describes how she felt GPs are in need of training and awareness around eating disorders and Asian females:

“Nothing, no. So I think that service needs a bit of a shuffle up in terms of the GPs….the GPs probably need to have a bit more training and awareness that these issues exist and perhaps if they nip them in the bud earlier they can prevent them from lingering”. Afshan, (Parent/sibling 6),Mother ,210

Resources

Many professionals raised concerns around lack of resources, including shortage of staff and training which affected delivery of services.

“ well the two main ones, again because I would say recently cuts have affected the amount of services that are available and agencies we can refer to which is a big problem”. Sue, (Prof 8),College Counsellor, 46

Health Care professionals felt they were already overloaded and could not take on other issues mainly due to lack of experience and budget cuts.

They don’t want change (workers), they are quite happy the way things are they don’t want change. They are saying they’re too busy, they haven’t got time to be taking on another issue and working, and that they are already overloaded as it is. But my view is, at the end of the day, these are service users. They need a provision and we’ve got to provide it as service providers, regardless of how much work it is. They’ve got to try and change. And change is something that a lot of people can find quite difficult to acknowledge or go through. Cos you’re so used to one way. Gulshan, (Prof 5),Senior Outreach Worker, 29

GPs were perceived to have pressure of time allocation for each patient and also budget constraints. Therefore were not always able to pick up on the signs around ED and Asian female’s and only treating/diagnosing common issues.

There are pressures on GP’s, there are pressure on prescribers you know - the Health Authority say you can only prescribe So? many, if some of these girls need in-patient stay again the challenge is there. It’s multi-faceted and I think the problem is…cannot be dealt with just by one health care professional group - it really is multi-disciplined approach. Dr Khan, (Prof 17),General Practitioner, 53
Amongst the community there was a common belief that GPs try to spend as little money as possible on treating and referring their patients:

“Since they’ve (GPs) received the money, the funding for each patient, you know where they have the purse strings for every patient? The care of patients has gone very cheap where they were referring you to hospitals. But now what they tend to do is give you the cheapest form of medication to start off with and then; it’s like you are constantly going back to the doctors, ‘it’s not working doctor’, ‘oh ok try this one’, which is slightly more expensive than the other medication. They send you off with that. So now all they seem to be doing is seeing how much money can they spend on each patient”.  
Kiran (Parent/sibling 3) Sister, 287

It was highlighted that only a limited number of sessions of specialist care were provided as there might be budget constraints and staff shortages. There was a lack of understanding and knowledge of Asian females with eating disorders among mental health service providers and support sessions were perceived to be too few and far between to make any difference.

Afshan also complained about her daughter only having two sessions with the dietitian which she felt was not enough to make a change in her daughters eating pattern:

“Well the service is...No point going to be honest in my opinion. You get two sessions”. Afshan (Parent/sibling 6), mother, 56.

For those South Asian females who live in close knit communities, and a small town that does not provide a specialist service for eating disorders, it is difficult to access services:

“Young people I mean like twenty and over who had eating disorder, unfortunately there is no service in (Town)especially in the voluntary sector and sometimes people don’t want to approach the statutory services”. Shabnam, (Prof 2), Mental Health Advocate,52

However, where training did exist, it was seen as limited. For example focusing on hitting targets, rather than in how to communicate and work with clients more effectively:

“There is something about mandatory training that the organisation means you have to do it in order that it meets its targets but it’s in the interaction
with patients that you learn far more; and colleagues you learn more”. John, (Prof 13) Psychotherapist, 139

Even training that purported to be about cultural issues was viewed as superficial:

“No I think they are probably offering it more now but we didn’t really. We had…I should say we had something….the NHS acknowledge equality/diversity training; we had that but it was very superficial I would say. It wasn’t in-depth of the work we were doing with them. But they do acknowledge it and they do have”. Heather, (Prof 16), Private Counsellor, 108

Eating Disorder participants that did experience counselling did not find it useful in helping them manage or recover from Eating Disorders.

“She actually went to the doctors the other day …for some other reason. And then …the doctor was talking about ‘we have a counselling service here’ and stuff like that. Because obviously she…they give clinical supervision and they said, ‘it’s probably worth you talking to a counsellor’. She sat with the counsellor, counsellor basically she said it was almost role reversal because the counsellor ended up talking about her life and her problems and hers! And I said, ‘well did you get anything out of it?’ and she goes, ‘oh well no, not really’. You know? So”…Moona (Parent/sibling 7), Sister, 121

Due to lack of knowledge and experience in working with South Asian females with Eating Disorder, professionals do not always recognise the problem and therefore do not refer.

“Definitely, yes I would, absolutely, and I think it goes for all that staff. We definitely would give it more priority. Just like with everything else, but because we don’t know, we just tend to refer them to a…external agencies and organisations or just within our groups that are running on a weekly basis” Gulshan, (Prof 5), Senior Outreach Worker, 17

Kalsoom talked about how she understood the South Asian culture and how she is familiar with the issues and therefore is more engaged with the patients’ needs than her Caucasian counterparts:

“a white worker wouldn’t do that I will go the extra mile because I understand ...and I could...well no that’s wrong in saying that they understand but I can see where there are problems because I’m from that
Kalsoom also talks about how her Caucasian colleagues will refer South Asian patients to her rather than trying to understand and try and make sense of the patient and this made her feel frustrated:

If an Asian client walks through the door and they think [Caucasian colleague] there is something more here and I don’t understand this or this is what’s going on ..they [Caucasian colleague] will say right refer her to [her name] ..and she will look at it ..so I will look at the case and I don’t have an issue with doing that ..erm..I don’t feel used in that way but....then having said that erm ..it can be frustrating that you know ..that they ..that some people don’t go out of their way to really make sense of it”.

Shabnam describes how she continued to give support to an Asian mother of three suffering from long-term ED even though she is no longer on her case load:

“We talk on the phone, if she’s really upset she’ll ring me and say I want to talk to you and I said ok. I am going to ring you about one o’clock then. She’s not in any of our books now”. Shabnam, (Prof 2), Mental Health Advocate) 198-199).

Below Table 22 summarises the seven main service level barriers perceived, to accessing services and support from mental health services.

**Table 22: Summary of Service level barriers to accessing services and support**

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<th>Barriers</th>
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<td>Health Care professionals not being aware of ED as a South Asian problem.</td>
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<td>Service providers lack of confidence in meeting needs of South Asian females with ED.</td>
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<tr>
<td>Family member present during consultation</td>
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<td>Fear of being seen accessing services due to shame and stigma</td>
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<tr>
<td>Lack of trust and breach of confidentiality with health care professional</td>
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<tr>
<td>Fear of asking patient about ED symptoms as concern about cultural offending</td>
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<td>Difficult to carry out a physical exam/identify ED on women in traditional dress</td>
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6.5 Summary of overarching theme 2

The main overarching theme, barriers to accessing treatments reveals the perceptions and experiences of South Asian females into the potential barriers to accessing services. All participants expressed parents’ lack of understanding and support around eating disorders. Most females were not able to discuss their illness with their parents because they lacked understanding and therefore the participants feared they would react negatively and not be supportive in accessing services. Participants revealed a lack of trust in services which were perceived to be barriers to accessing services particularly services within primary care that should be first points of access (e.g. GPs). Their concerns were around confidentiality when consulting the GP a fear of exposing the family; lack of support and understanding from parents; lack of privacy to disclose problems to health professional, little or no confidence in limited mental health services, and a lack of language to express their concerns to parents in their first language, lack of cultural awareness in health professionals. Health care professionals admitted that they lacked experience in working with South Asian females with Eating Disorders and did not always look for initial signs of eating disorders. They were fearful of being culturally inappropriate and lacked trust that information shared with South Asian colleagues would be treated professionally. All professionals felt there was a lack of adequate tailored training and culturally appropriate or sufficient resources.
Section 4
Chapter 7

Overall Discussion and Conclusions
7.1 Overview of Chapter

Eating disorders are problematic conditions that are challenging to diagnose. Evidence indicates that the prevalence is increasing (Dolan, 1991) amongst South Asian women. Eating Disorders impacts on the individual, their family and society. Cultural factors such as family and media influences have been described as key to aetiology (Smolak & Striegelmoore, 2001), however research to date has largely focused on Western Caucasian females. Despite an increasing recognition of the occurrence of eating disorders among South Asian females, not only those living in Western countries but also among those living in their country of origin, research has largely omitted the study of this population. Women with Eating Disorders struggle to access mental health services (Fairburn & Cooper, 1982) and this is particularly true for BME groups (Brown et al, 2009, Lamb et al, 2014). The reasons for this and why treatment services fail to meeting the needs of these groups of women had, until now, not been explored.

The main aim of this thesis was to understand the issues relating to the development, maintenance of eating disorders and help seeking behaviour and barriers to accessing treatment for eating disorders among South Asian females, also family and cultural issues that might contribute to those barriers and maintenance or that facilitate treatment seeking and recovery. In order to develop culturally sensitive services, research examined the scale of the problem by conducting a systematic review (study 1) of the prevalence of eating disorders among South Asian in the UK and the Indian subcontinent and a qualitative review (study 2), examining the experience of the illness (see Section 2, Chapters 3 and 4). For Study 1, thirteen studies were identified. Overall, a higher prevalence of Bulimia was reported amongst Asian females in the UK compared to Caucasian females. However, studies conducted in Pakistan and India reported a lower prevalence rate of diagnosable eating disorders than reported in Western countries. The studies were variable in quality and, in particular, the review identified a need to consider the adaptation of measuring tools, as eating disorders may present differently in different cultures, and diagnostic criteria based on Western norms may not always be appropriate. In study 2, only three studies were identified the reviewed studies revealed important themes; cultural
conflict and controlling families. However the lack of qualitative studies and the finding that those identified were of extremely poor quality suggest the literature on the study of the experience of eating disorders in south Asian women is extremely limited. Consequently, Study 3 aimed to address this gap and investigate the experiences and perceptions of these women, alongside the experiences of their family members and health care professionals. It is important to note that data from the interviews only revealed barriers and no facilitators were reported. The study particularly focused on the psychosocial factors perceived to be important in the development and maintenance of these eating disorders, and the difficulties that the women experience in accessing services. Thirty-five participants (women with Eating Disorders, family members of South Asian women with Eating Disorders, and health professions working (or potentially working) with this client group) were interviewed and transcripts were analysed using Thematic Analysis (Braun and Clarke, 2006). Two overarching themes were identified with corresponding sub-themes; development and maintenance of eating disorders in the context of family and cultural conflict; barriers and facilitators to accessing treatment. The main reasons behind the development and maintenance of Eating Disorders encountered by South Asian females were around conflict with family and culture. Seeking treatment was difficult for these women due to stigma, shame, issues of confidentiality and lack of training and understanding in cultural competence among health care professionals.

The following section discusses the findings in the light of the literature and considers the strengths and weaknesses of the work, clinical implications and areas for future research.

7.2 Discussion of qualitative study 3

7.2.1 Development and maintenance of eating disorders in the context of family and cultural conflict.

Many young Asian females in Britain today were either born here or grew up here from an early age (Ghuman, 1991). The results of study 3, highlighted that South Asian females had a mixed Western and Asian cultural mind-set which often
conflicted with their parents’ very traditional views, and who fear losing their culture. The clash between the essentially Western values of freedom of choice, personal fulfilment and self-development and the values of loyalty and obedience to the family was discussed by most of the participants. The findings from the qualitative work revealed that the women with Eating Disorders struggled to manage living this dual culture and felt that they had no or little control over life choices. The data revealed that the eating disorder behaviours potentially served as a way of attempting to manage the distress experienced, in particular as a way of trying to exert control or coping that becomes integral over time and impacts on their mental health. These cultural issues seems to be greater and more common among South Asian females and were perceived to be contributing to the onset and development of their eating disorder thus by eating less these women felt they were exerting some control over their lives.

7.2.2 Conflict with family traditions

In the West, children are encouraged to develop critical thinking and a questioning attitude, as opposed to unquestioning respect for elders (Ghuman, 2000). This was particularly relevant in the qualitative data in relation to making own life choices: a choice of whether, when and who to marry, and choices over pursuing a certain career within a culture that promotes early marriage and values marriage so highly. Parents were perceived as trying to ‘mould’ their daughters’ behaviour and personality so they could easily adapt to married life, and in order for this to happen, they ultimately sought to decide the choice of career, friends, how they should dress and life partner. This lack of control has previously been suggested as a contributing factor in the development of anorexia nervosa in South Asian females (Littlewood, 1995). The findings of this study lend evidence to this theory and demonstrate that the problem persists.

In their study, McCourt and Waller (1995) showed that perceived maternal control among Asian girls helped to explain the differences in their unhealthy eating attitudes compared with the Caucasian girls. They found that older girls (aged between 14 and 16 years) but not the younger ones (aged 12-13) perceived their parents as “more controlling” than did Caucasian girls. Similar parental restrictions
were revealed in the work presented in this thesis which prompted participants to control their eating and were perceived to result in the development of eating disorders. Participants also reported keeping some aspects of their lives, particularly the extent of their eating behaviour and attempts to access health services for treatment, secret from family members for fear that it might bring shame and dishonour to the family. When parents believed that this ‘illness’ was self-inflicted, it made them even more frustrated and annoyed with their daughters. Since, over time, restricted eating impacts on the physical appearance, parents were concerned how their daughter’s ‘behaviours’ might be perceived negatively by the Asian community thus further hindering their daughters chance of marriage to a perspective suitor. In this way, the interactions the women were managing within their families were closely linked to not only their parents’ beliefs, but also those of the wider South Asian community. The close relationships within communities exacerbated the challenges the women and their families were struggling with, as the parents perceived pressure form the Asian community to adhere to certain traditions like arranging marriage for their daughter.

The findings revealed that parents’ were perceived to fear losing their culture to be the main reason for their controlling behaviour towards their daughters as they are expected to carry on traditions with their children. Therefore becoming ‘Westernised’ would mean loss of the Asian culture. Dasgupta (1998) argues that there is a great deal of pressure on Asian females to maintain traditional roles and identities as they are believed to be the “carriers” of cultural values and tradition within families. They may be exposed to freedoms in the UK which conflicts with the role expectations of the Asian family (Ahmed & Lemkau, 2000). This study reveals how this pressure can potentially manifest itself in problems such as Eating Disorders. In reaction to this control, some women withdrew from their family. Some attempted this by conceding to demands and expectations (for example agreeing to get married even when they were unhappy about the choice). Others felt unable to live in the situation and left the parental home. The consequences of this were often complete loss of contact with family and friends. In either situation, the distress and hence eating disorder often persisted, however, there were examples where leaving home removed barriers to accessing services and enabled the women to access and benefit from help.
The study’s findings fit with those of Munuchin et al (1978), who described a group of family system characteristics that reflect the family dynamics of patients with anorexia nervosa: enmeshment, overprotectiveness, rigidity, and avoidance of conflict and lack of conflict resolution. These four transactional characteristics provide the context for the anorexic child to use her illness as a means of communicating avoided messages as well as family and parental conflict (Blinder, Chaitin & Goldstein, 1988), and were also evident within the data about family dynamics for South Asian women.

Enmeshment is where family members are highly involved with one another. There is excessive togetherness, intrusion on other’s thoughts, feelings and actions, and overall a lack of privacy (Minuchin et al 1978). This was perceived by many participants, where they felt they did not have personal space or thoughts, due to these being intruded upon by parents. A child growing in this type of family learns that loyalty is of primary importance. This pattern of interaction hinders separation and individualism later in life (Blinder, Chaitin & Goldstein, 1988). Overprotectiveness refers to the excessive nurturing and protective responses commonly observed. Pacifying behaviours and somatization have elsewhere been described as prevalent amongst this group (Weiss, Katzman & Wolchik, 1985). Parents in the current study were perceived as being overprotective through controlling the women’s main choices in life, for example, choice of career and marriage plans.

The South Asian women interviewed during the course of this research acknowledged that these pressures were distressing and led them to want to take control of their lives. In order to cope with these pressures participants described controlling their food intake as a coping strategy. By eating less they felt they were exerting some control over their lives and a way of relieving their stress. It was also a way of protesting against the pressure of not being able to make their own life choices and they also used it as a way of keeping slim. These control and cultural conflict issues seem to be both greater and more common in South Asian culture and were perceived to be contributing to the development and maintenance of eating disorders in this group of women. This also supports the systematic review findings, reported in Section 2, which revealed that prevalence of diagnosable eating disorders was greater among South Asian females than among Caucasians living in the UK.
7.2.3 Commodity – marriageability and marriage

Girls are either seen as an economic burden or valued as capital for their exchange value in terms of goods or money in very poor South Asian families (Rao and Deolalikar, 1998). A combination of cultural, traditional and religious arguments may justify an arranged marriage at an early age. The fear and stigma attached to premarital sex and bearing children outside marriage, and the associated family honor, are often seen as valid reasons for the actions that families take (Ghuman 2000). Marriage is generally viewed as a permanent arrangement, and divorce rates, although rising, remain very low in South Asian communities (Babb et al 2006). In the qualitative work presented within this thesis, expectations of marriage and the importance of being perceived within the community as marriageable pervaded the data and was a core source of conflict for the women. The women interviewed perceived themselves to be a burden to their families and felt an obligation to be viewed as marriageable without any suggestion of ill health (physical or mental). They also were acutely aware of their cost to the family because a dowry would be required at the time of marriage.

In most South Asian communities, educational, class, religion, culture and mutual relationships between the families of the potential bride and groom is of greater importance than the personal likes and dislikes of the partners. Thus in South Asian cultures, marriage is a very important life event (Berthoud, 2005) and parents feel that they have a duty to ensure daughters are raised to be ‘good’ wives and daughters in-law, which involves a minimal level of education. The data revealed that social pressure plays a significant role in the daughter getting married by a certain age, and if she remains unmarried, extended members of the family and community may begin to doubt her chastity and health. Therefore, parents perceive pressure to protect their daughters from criticism. In this study, the pressure of having to please her parents by being an obedient and dutiful daughter was perceived as overwhelming to the individual and appeared to affect their mental well-being.

Traditionally in Asian culture, curvy women have been viewed as ‘healthy and wealthy’ but increasingly they are being perceived to be unhealthy; it has been argued that this change has been filtered through the media, in particular television
(Dasgupta, 1996). Television in the UK now offers many channels giving access to numerous programs from around the world. Asian networks have now become much Westernised in terms of ‘size zero’ TV personalities and Bollywood actresses. There has also been a shift from wearing traditional Asian clothes like sarees and shalwar kameez to more fitted, or revealing Westernised attire. Asian females are bombarded with size zero images from both the Western and the Asian media, which are perceived as pressure to aspire to a slimmer body image. In study 3, physical appearance was perceived by participants to be very important, in particular having a slim figure, fair skin and being tall. Participants perceived these to be signs of piousness, fertility and not being greedy. Mandelbaum (1988) and Goody (1990) argued that in Asian culture, constraints on women’s autonomy might actually increase with affluence as such families seeking higher education for their daughters, in part as a dowry equivalent.

To ensure best marriageability, participants in this study often felt that they were treated as a ‘commodity’ by their parents and family members, with the main emphasis on physical appearance, a thinner body shape and having a good level of education. This pressure to be thin was perceived by the participants to have contributed to the development and/or maintenance of their eating disorder. Parents plan for their daughters’ marriage very early on in terms of saving and looking for a potential suitor, putting the word out to the community, thus the importance of maintaining a good impression about the family and in particular the health and attributes of the daughter starts early in a women’s life. It is therefore, important that any mental health issues that the daughter may have are hidden from members of the community as this would harm their potential for a ‘good’ marriage proposal. In this study, this was perceived as a pressure by parents and the young women themselves and therefore they kept health issues a secret both from the community and their own family, and this made them reluctant to seek help and or access services.

Often when an Asian woman marries, she leaves her parents’ home to live with her husband’s family, and takes on a role of caring for his parents in their old age. Once married, these young brides are expected to be submissive to their husband and work hard for their in-laws’ household, including keeping it clean, cooking for all the family and looking after the needs of all members of the household. In this study,
married participants living with in-laws talked about the pressure and control from their in-laws, which impacted hugely on their well-being. Their day to day activities were monitored and controlled particularly by the mother-in-law. Not only did these young women experience control living with parents but they also experience this living with in-laws. Married participants encouraged their husband to leave home and set up their own household but this was not considered to be the “done” thing as sons are expected to look after their parents and this would be frowned upon by members of the Asian community. Some participants agreed to the pressure to get married in order to escape control by their family but as these participants had no choice but stay within the in-laws home, they continued to endure control and this was perceived to contribute towards development and maintenance of eating disorders.

7.2.4 Managing contrasting cultures and community

Within the South Asian culture, the structure of families is different to that of British culture and children are raised with a strong sense of obligation to their parents, their family and the wider Asian community (Durvasula and Mylvaganam, 1994). This collectivist value system has implications within the family and community relationships (Ahmed & Lemkau, 2000). Western cultures may be regarded as holding values that conflict with Asian culture as they place emphasis on personal responsibility and individual autonomy (McCourt & Waller, 1996) whereas within Asian cultures this does not exist (Dasgupta, 1998).

It has been argued that second generation Asians growing up in the UK as a minority group differ from the first generation with regard to expectations placed on them and their attitudes, for example support from the community might be viewed as being intrusive and/or restrictive (Furnham and Sheikh, 1993). Indeed, participants in this study discussed the existence of this dual culture and there was lack of recognition and discussion of this with parents. Parents often failed to recognise this pressure of fitting into two cultures as their experience had been different, and they then became frustrated at their daughter for not adhering more towards the Asian culture.
It seems that the root cause of the conflict between home and Western values is the fact that the Asian family encourages ‘interdependence and collectively’, whereas Western society emphasises individualism and personal autonomy (Triandis, 1991). Young Asian females are brought up in such a way that they grow up to be obedient daughters and uphold the honour of the family (Dosanjh & Ghuman, 1998). Their schooling and up-bringing is planned in such a way that they would make faithful and conforming wives. As mothers, they are expected to be completely devoted to the care of children and of the extended family (Shaw, 1990). The constant battle of trying to fit into two conflicting cultures was perceived to be very difficult to maintain by participants and this led to leading an almost double life, where life outside the family home was kept a secret from the family in case there would be negative repercussions like intensification of control. For most participants this pressure led to issues around eating and in particular contributed to development of anorexia and bulimia.

Mumford et al (1991) found Asian school girls were significantly more likely to have an eating disorder than Caucasian females. Asian girls from traditional backgrounds were more likely to exhibit higher scores on the Eating Attitudes Test (EAT) and the Body Shape Questionnaire (BSQ) compared with their Caucasian counterparts. They suggested that this was due to cultural conflict, the idea that traditional values of collectivism and interdependence conflict with Western goals of individualism and independence (Ballard, 1979), and that exposure to both traditional family values and more “liberal” Western values can cause confusion and distress. This suggestion was supported by the qualitative work undertaken during the thesis.

In the current study, community members were perceived by participants to blame the parents if the daughter got ‘out of control’ particularly the mother. Support for the family in terms of emotional and community links were likely to be withdrawn from the family. Anyone seen or heard to associate with the family could also be potentially labelled as bad parents. Therefore the families’ links with the community were perceived to be essential to gain support but also to keep ties with the Asian culture. Hence it was important to give a good impression of their daughters to the community in order to keep these ties strong.
The women with Eating Disorders in the current study, perceived conflicting pressure from the Western and Asian culture on their role in life. Participants perceived control from their parents such not being able to make important life choices but on the other hand, they perceived the pressure of Western values to be independent. With this dual pressure, participants found themselves being secretive about their activities outside the family home, and some thought about running away because they could not cope with the control and the pressures that were put on them. Two of the participants had left home. Studies have suggested that ethnic identity is an important factor in the eating psychopathology of Asian females, for example Ahmed et al (1993) and McCourt et al (1995) found that Asian females living in the UK have more unhealthy eating attitudes than Caucasian females, highlighting that these differences may be due to cultural clash. Littlewood (1995) argues that due to this conflict the female searches for internal control which cannot be governed by anyone. According to the present study this internal control is exerted through food intake. This research indicates that women who tried to fit into both Western and Asian culture, in particular the experience of integrating the conflicting demands of a controlling family home and Western society, experienced psychological stress. Due to the unique stressors and cultural conflicts that these participants faced they were particularly vulnerable to experiencing a considerable level of distress which appeared to, trigger or maintain an eating disorder.

7.3 Barriers to accessing treatment

Participants interviewed reported relatively limited experience of receiving effective treatments, but had many experiences and ideas about the barriers to accessing treatment. One of the major barriers discussed was that eating disorders are not recognised or understood in the South Asian community. In many South Asian languages, no word exists for the problem and individuals with these as first languages struggled to conceptualise the problem. Health care professionals also thought they were not experienced or trained enough to meet the needs of these individuals and this led them to avoid trying to identify or discuss it with patients. All participants talked about eating disorder problems being unacknowledged, ignored or unaccepted within their families. Given the importance of family within
this culture, eating disorder sufferers whose families were not supportive felt particularly isolated.

There was much discussion by participants around lack of privacy when consulting with a GP and risks of and breaches of confidentiality, particularly within primary care. Participants talked about certain issues as relationships before marriage and conception of children outside marriage, and they felt not all Asian GPs may be sympathetic to patients who are seeking contraception. Although confidentiality is central to trust between doctors and patients, some South Asian patients are clearly reluctant to approach their GPs if they are well known by the wider family or community. As the Asian culture is perceived as a collective system, it operates with strong shame and honour values and these evidently could act as barriers to problem identification and accessing services. A key barrier for these participants in seeking help from their GP was the fear of breach of confidentiality. This particularly arose in situations where the GP was of the same ethnicity, where the family was registered with the same GP or where the GP was a friend of the family. Breach of GP confidentiality has also been identified as a barrier to accessing treatment among South Asian women with psychological stress and self-harm (Chew-Graham et al 2002) and among patients suffering from Chronic Fatigue Syndrome (Hannon et al 2012). Even if most Asian GPs do not divulge confidential information, the perception that they may do so, is a barrier for some to access the health service. Some patients view their GPs as Asian first and doctor second. Interestingly, the data showed this view was also held by mental health workers who lacked trust in how confidential information would be handled between primary and secondary care.

A review by Brown et al (2009) discussed how mental health services for eating disorder sufferers were underutilised by ethnic minority groups. They speculated this may be due to mental health professionals holding the beliefs that ethnic minorities are protected against Western beauty ideals and are therefore unlikely to be affected by eating disorders. The perceived rarity of the condition also places strain on the GP’s ability to identify cases. Reid et al (2009), in a qualitative study involving twenty GPs, found that the infrequency with which GPs saw patients with eating disorder symptoms, and consequently, their lack of preparation, were some of the many barriers to patients receiving treatment. Other reasons were the secrecy that
surrounds eating disorders and the reluctance of sufferers to seek help, as well as long referral waiting times and lack of family support. The current research highlighted that one key barrier to accessing services for these groups of women was related to family honour and this was linked to confidentiality and the fear of others finding out about their illness.

7.3.1 Exposing the family: bringing shame and failing to please

Participants in the qualitative study described having experienced parents reacting in anger and confusion when they learnt about their daughters’ illness. They blamed their daughter as the eating disorder was perceived to be self-inflicted and thus parents would force their daughter to eat and ‘pull herself together’. It was also something the parents did not want extended members of the family or community to become aware of, as this would bring shame on to the family. This was mainly perceived to be due to the lack of understanding of eating disorder and that this is a mental health problem. After the initial reaction of family members where they would ignore the problem, some individuals withdrew from the family and began secretly trying to manage their eating disorder, but if they were unable to control their illness and their symptoms became worse than at this point, they would try and access services alone. Only two sets of parents in the current were forced by circumstance, to support their daughter to access services due to the severity of her symptoms (i.e. deterioration of their daughters’ illness). Most participants talked about how they felt isolated and alone in their illness journey and how they would avoid any conversation relating to eating with their family because they feared any further repercussions.

Minuchin et al's (1978) fourth main characteristic is avoidance of conflict and lack of conflict resolution. Here families have a low tolerance for overt conflict and lack of conflict resolution strategies. Thus problems are often left unresolved and are prolonged by avoidance manoeuvres (Blinder et al 1988). The need for change is denied, thereby preserving accustomed patterns of interaction and behavioural mechanisms. Rigidity is commonly observed in the family cycle during periods of natural change where accommodation is necessary for proper growth and
development. Such an example would be when adolescent individuals begin to want more independence and have freedom to make life choices.

Those participants seeking treatment perceived it to be drawing attention to and exposing the family, and in particular causing shame. Shame and stigma are concepts that are often quoted in the wider mental health treatment seeking literature as well as specifically to eating disorder treatment (Hepworth & Paxton, 2007). Even though feelings of sadness, stress or worry can be experienced, these feelings are not always openly communicated outside the family (Laungani, 2007), therefore, help seeking may indicate a failing to comply with cultural norms. Izzat is defined as the ‘honour’ experienced by others in one’s family by one’s own behaviour and there is often great pressure among women in South Asian cultures not to bring shame or reduce izzat within the family (Chew-Graham, Bashir, Chantler, Burman & Batsleer, 2002; Gilbert, Gilbert & Sanghera, 2004).

In the current research, health care professionals and participants with eating disorders described parents accompanying their daughter to the GP and sitting in the consultation room listening to what was talked about, which then makes it difficult for the young female to openly talk about her health issues. This is an apparently normal practice and many older Asian GPs are accustomed to this and understand the need for parents to accompany their daughter. However non-Asian and younger Asian GPs find this frustrating as they cannot have an open consultation with their patient and do not always ask the parent to leave as this may lead to further conflicts between the two. The daughter may not be permitted to visit the GP again, resulting in the patient falling through the net. Participants were afraid to access services without the knowledge of their parents because they might be seen by family or community members and this may get reported back to the parents resulting in more distrust and anger between the daughter and her parents. Raising awareness about eating disorders particularly around the various trigger factors among parents and the South Asian community may reduce the risk of parents feeling ashamed.

Participants with eating disorders acknowledged that they had severe eating problems in the form of anorexia and/or bulimia; all of them experienced related health problems including severe weight loss, amenorrhea, and arthritis and severe
damage to dental enamel. Most participants also self-harmed in the form of cutting and/or burning. Having these health problems, the participants still avoided professional help especially from their family GP as they feared they would inform their parents or other members of the community. Protecting the family honour, shame, fear of exposure, professionals’ breach of confidentiality and family control influenced the participants’ help seeking behaviour.

7.3.2 Lack of support and understanding from family

It was also evident that parents did not understand the terms of eating disorders, anorexia, and bulimia. The psychiatric definition of anorexia can be viewed as socially constructed through language and the different forms of knowledge that have emerged throughout different historical periods in Western society (Hepworth 1999) but there is no definition or a particular word to describe this in any South Asian languages, which contributes to the difficulty to understand this illness. Raising awareness through appropriate information aimed at the Asian population would help increase understanding, possibly lessen embarrassment and shame and might increase service uptake.

7.3.3 Problems in service provision for South Asian females experiencing eating disorders

Professionals highlighted that young South Asian females have very complicated needs which should be addressed. These include stigma, barriers, culture, religion, behaviour and acceptance in relation to their appearance. Culture and acceptance are contributing factors as are family and community influences. However there was little awareness among professionals and parents of how South Asian females are affected by eating disorders. There was also discussion around educating professionals on cultural and religious issues of these groups of females and therefore, it is important to develop specialist services to meet their needs.

Health care professionals interviewed openly talked about their lack of knowledge around Asian females and eating disorders and the issues around Asian culture. They discussed the need for in-depth training and in particular for GPs to pick up on the
early signs of eating disorder among South Asian females. Becker et al (2003) in their study of access to eating disorder services for ethnic minorities found that clinician bias may be an important factor; in the current study there was evidence of denial amongst some health care professionals of South Asian females experiencing eating disorders.

Many participants had the impression that their GP was not helpful or approachable. Parents interviewed complained that their GP did not investigate further in relation to their daughter when presented with the fact that she was not eating enough, gaining enough weight or late onset of puberty. They were simply told it was ‘a phase’ and they would grow out of it. Initial assessments were not carried out including measurement of weight. Many health care professionals and GPs that were interviewed admitted GPs tended to look at somatic issues rather than psychological factors. Moreover, that, non-Asian GPs found it difficult to diagnose and examine as many Asian females ‘cover up’ by wearing loose traditional dress.

Some participants also talked about GPs breach of confidentiality which was perceived to be a common practice among the older generation of Asian GPs. In the current study, health care professionals felt that the first generation of parents and the older GPs have a unique understanding as they are from the same generation. These GPs treat the family rather than view each member as an individual patient. Participants stated that because of this, it is important for them to ensure Asian female patients are adhering to cultural and religious expectations and sometimes this can result in breaches of confidentiality. However, younger Asian GPs perceived that the second generation of patients are more open and tend to talk about their problems in detail with fewer feelings of embarrassment or shame.

There was much discussion around non-Asian professionals being unable to relate to their South Asian clients and the difficulty in understanding their cultural and family issues. Although some had undergone cultural competence training, this was described as superficial and they believed a more useful way to gain understanding was to work with Asian clients and learn from Asian members of staff. In contrast, health professionals from South Asian community were engaged with patients and felt they had a shared understanding the culture and hence demands on the women.
However, these staff did not feel they had been trained or were qualified to intervene with clients. Evidently there is a need for more South Asian counsellors and psychiatrists working in this field with adequate training in these problems. The few South Asian staff who were in higher positions felt overwhelmed with treating mostly Asian clients and sometimes these front line staff would go over and above their line of duty, for example interpreting for non-Asian staff or continuing to work with discharged patients.

There was also a lot of discussion around the lack of resources including the closure of the small community projects in deprived areas due to no funding availability. These projects when the community links to health information, in particular mental health and an opportunity to socialise and enrol onto small educational programmes leading to further education or employment. For young Asian females, it provided an opportunity for them to discuss issues like eating disorders, family conflict and control, with staff as well as take part in social activities.

This highlights the need for improving links between eating disorder services and community services to enable raising awareness and ways of supporting the eating disorder sufferer. Providing appropriate eating disorder awareness to front line staff at community centres, community workers and most importantly, GPs as well as sign-posting them to specialist services, seems fundamental for South Asian communities.

In the current research participants seemed to have experienced a unique combination of stresses, with over-controlling parents and expectations of keeping slim and beautiful for marriageability prospects, being an obedient daughter, wife and daughter in-law, lack of control in making own important life choices and trying to fit in two conflicting cultures. These pressures were perceived to be overwhelming for participants and they experienced considerable psychological distress, which was considered to have triggered and maintained their eating disorder. Although participants had relatively limited experience of receiving effective treatment, they perceived key barriers to accessing treatment were lack of understanding of eating disorders among family as well as health care professionals, breach of confidentiality
particularly in primary care, protecting the family honour, shame and fear of exposure. All these factors influenced the participants help seeking behaviour.

7.4 Methodological considerations

This section addresses the significance of the findings, methodological issues, strengths and limitations of the present research and suggestions for future research. The thesis utilised two main methodologies. First a systematic review and secondly a qualitative interview study.

7.4.1 Strengths

The epidemiological review had a number of strengths; it was conducted systematically following the MOOSE guidelines (Stroup et al 2000) for reviewing observational studies. A range of specific search terms were used in order to carry out appropriate publications, and used electronic database search engines to carry out in-depth literature searches. Good inter-rater reliability was established about applying the inclusion and conclusion criteria to determine which studies would be included in the review. The extracted data from the included studies were also assessed to ensure it was being undertaken systematically. Inter-rater reliability of quality assessment was also established independently with another researcher. Cultural sensitivity of the methods used by the selected studies was also assessed, and this is the first reporting of this approach and hence represents a methodological advancement in systematic reviews in cultural groups.

Alongside the quantitative review, an attempt was made to identify and review any qualitative research. The main strengths of this endeavour were that the selected studies were appraised in accordance with Critical Appraisal Skills Programme Criteria (CASP 2013) and guidelines developed by Walsh and Downe (2006). An inter-rater reliability check was also conducted on this and demonstrated 100% agreements between the supervisor and the researcher.
The qualitative interview study is the first attempt to systematically collect and analyse qualitative data about ED in SA communities. For such a study, the sample was substantial and the data rich. Data from three groups of stakeholders, patients, relatives and healthcare professionals, were gathered. This triangulation of data enabled the researcher to capture the similarities in experience and knowledge around South Asian females and eating disorders and look at the experience of ED amongst the South Asian community through different lenses (Peters, 2010).

The topic is potentially highly sensitive, however all participants spoke openly about their perceptions around their experiences of eating disorders from participants with eating disorders to parents and siblings. In particular, health care professionals were very honest about their lack of experience and knowledge of working with South Asian females with these problems and the need for more training to improve this. Due to the sensitive nature of the topic area a rapport was developed with the participants as this is considered important in enhancing the researcher’s accesses to the participant’s lives and building trust (Seidman, 2000). The main techniques to achieve this were through demonstrating care and empathy (Dickinson-Swift et al, 2007), including not interrupting the participant during the interview, respecting periods of silence and using open ended, clear and aimed questions (Patton, 2002). The fact that participants could speak so openly, is testament to the quality of the interviewing and success of this approach.

Recruiting members of minority groups to participate in research is extremely challenging (Brown et al 2014, Waheed et al, 2015). The researcher did experience difficulties in recruiting from this population and recruitment took far longer than expected. To address this, multiple methods were used to identify and engage participants, like recruiting from South Asian women’s groups, local Asian radio and newspapers. A novel aspect of the study, which is likely to have increased recruitment, is that the researcher is South Asian. This enabled her to access groups not easily approached by non-Asians (e.g. Asian women’s groups). Being a native speaker of Urdu and Punjabi enabled her to talk to potential participants about the study in their own language and there was an understanding of shared experiences and that they could identify with her. Ethnic matching has been argued to be important in the conduct of research, because it is believed that the quality of the
data will be improved as matched interviewers have a greater potential to understand and emphasize with participants’ circumstances, cultures, and experiences than non-matched interviewers (Elam & Fenton, 2003, p.22). Ethnic matching can also be problematic, as it may result in the respondent providing socially desirable responses, under-reporting of certain types of behaviours (e.g. relationships before marriage), one or two-word responses, and concerns about future contact with the interviewer in other settings (Elam & Fenton, 2013). However, during the interviews, although primarily conducted in English, non-English participants could draw upon words and phrases from the South Asian language and would understand them. This may be particularly important as there is no specific word for eating disorder in Hindi, Punjabi, Urdu and Sylheti so participants may have wanted to draw upon a wider vocabulary and phrases, not necessarily in English.

7.4.2 Limitations

The main potential limitation of the epidemiological review was that only studies published in English were considered which may have limited the number of studies included. Although the inclusion of studies written in Urdu, Hindi and Bengali would need to be translated into English which would have been time consuming and costly, they may have offered further insight into the prevalence of eating disorders among Asian females and the tools administered. It should be noted however that no such study appeared in the searches.

Sample size is also an issue to consider in terms of overall limitations in relation to the qualitative work presented within the study. Although substantial overall, the final sample, comprised only three interviews with parents all of whom were mothers. This is a limitation as data from the women and siblings suggest that both mother and father play key roles in the development and maintenance of eating disorders, particularly within the South Asian culture. They were also implicated as a barrier to accessing healthcare. Recruiting parents proved particularly challenging, possibly because of their lack of understanding of eating disorders and unwillingness to discuss it. However the interviews that were conducted did capture the parent’s perceptions of managing a daughter with eating disorders and hence represent an important lens on the problem. All three interviews were with mothers and a
particular limitation of this work was failure to recruit any fathers. As fathers may have different networks within the community than mothers. Interviews with siblings were particularly rich and provided a non-patient view of the family dynamic, but again, only sisters were recruited and it was not possible to recruit any brothers and this may have highlighted issues from a different perspective as brothers have different gender expectations and hierarchy within the home, the Asian community, as well as the wider British society. It is not possible to generalize these findings to all South Asian females with eating disorder, family and health care professionals. However this was not the aim of the researcher rather it was to generate ideas of potentially relevant obstacles for South Asian females to access eating disorder services.

A further limitation of the research presented within the thesis is the extent to which a sample that comprises participants from different cultures can be considered together as a ‘culturally-bound’ group. The term ‘South Asian’ fails to recognise the diversity that exists within South Asian communities (Marshall & Yazdani, 1999) as the present sample included a range of ethnicities from the Indian subcontinent; Indian, Pakistani and Bangladeshi, who varied in religious beliefs, spoken languages and customary practices. However all participants with eating disorders were South Asian and identified themselves as this and therefore formed a cultural group. Although every participant's journey was unique, however in accepting that a cultural group exists and that there are shared ideologies as defined by culture, there may be cultural specific obstacles that can be identified. Further work is needed to explore how the disorder develops and is manifested in sub-groups and also amongst those living within the West and Indian sub-continent.

7.5 Clinical implications

The findings presented in the thesis have important implications in relation to the understanding of parents and sibling in the context of eating disorders. They reveal that eating disorders is a prevalent problem for women from South Asia, particularly those living within the UK or other Westernised country. However, this is not necessarily recognised by healthcare professionals and women may not present in
the same way as their Caucasian counterparts. There is a suggestion that this may be particularly problematic for second generation compared with first generation women.

Mental health care professionals may be more familiar with the experiences of non-Asian Western females with eating disorders. Although there are some similarities between Asian and Caucasian females, for Asian females various cultural barriers like, stigma, shame and issues of confidentiality, are evidently obstacles in the way of accessing services. As a result many of the Asian females experienced eating disorders over a long period without or with very limited access to treatment. Particularly this was because they had difficulties in disclosing their illness to anyone. Mental health professionals need to understand these cultural difficulties, which may also continue during and after treatment and therefore they need to be sensitive to these issues, when treating these groups of women.

The current research suggests that non-Asian mental health care professionals struggled to relate to their South Asian clients and had difficulty understanding their culture and family issues although some had cultural competence training this was described as superficial, therefore further training and supervision in treating South Asian females would help increase their understanding. Healthcare professionals also need to help increase awareness of the disorder in this cultural group as lack of parental support and understanding was also one of the key barriers to accessing services.

Findings also have implications for professionals working with parents and siblings; how professionals might support parents in making sense, talking about and sharing their experiences. This seems relevant given that the findings suggests parents were perceived to lack understanding of the illness, although they expressed frustration and anger they did want to help support their daughter. This highlights the need for professionals working with parents and sibling to be mindful of what would be helpful to parents and sibling both those who appear to be asking for support and others who may not feel able to directly request this.
Specific aspects of parent and sibling experience remains relatively under-explored, professionals working clinically with parents and siblings can provide ongoing development, research and evaluation of possible.

**7.6 Suggestions for future research**

The findings of the qualitative work in particular highlight the views of South Asian females with ED, health care professionals and parents and siblings regarding the development and the maintenance of Eating Disorders. Future research to expand on the present study is outlined below. Study 1 highlighted that epidemiological data on South Asian eating disorders is limited and the inconsistency in help-seeking revealed in study 3 emphasised that this is likely to under-represent the actual prevalence. The limited range of and quality of qualitative work found through systematic search in study 2 suggested this lack of knowledge relates to both the scale and the nature of the problem. Successful treatment of Eating Disorders in both Western and South Asian patients requires practitioners to ‘treat the whole person’ and is not resolved by focusing treatment on physical aspects of the condition (Tierney, 2008). Another key role for qualitative work is to provide health care providers with a wider background that allows them to understand the patients unique experiences, therefore an essential first step in both testing the relevance of testing the relevance of wider theories of Eating Disorders and understanding the specific elements of aetiology, access, treatment, recovery, and outcomes in South Asian females with Eating Disorders. The challenges of cross cultural research can themselves lead to an emphasis on descriptive accounts in qualitative work (Nasif, 1991). Engaging with the intricacies of Eating Disorders in South Asian community while challenging, also has the potential for developing methodological insights or approaches that may be valuable in wider cross-cultural work.

The limitations found in study 2 in literature and theory highlights the qualitative accounts of study 3, with further analysis and primary work can move toward developing grounded theoretical insights on which future work could build. This will be important since it allows researchers to compare conceptual insights not only in different populations, but also across different conditions in the same population.
Future research to expand on the study is outlined below.

- There has been no qualitative study to date examining the experiences of British South Asian females with eating disorders or understanding the role of family and sibling in the lives of these females or perceptions of health care professionals about potential barriers and in particular facilitators to accessing care for this population. Therefore, there is a need to replicate the current study within different parts of the UK in order to enhance this research with particular focus on facilitators to accessing services not just barriers.

- There is also a need to further explore the needs and experiences of siblings, in particular brothers who were missing from this study, and who may contribute as a carer as well as a go-between parents and the eating disorder sibling.

- Further work is also needed to investigate the experiences and perceptions of South Asian parents of eating disorder sufferers, particularly how parents perceive eating disorders, how they engage with eating disorder services and their experiences of family therapy. The current study recruited only three parents, all mothers. Further work is also needed on fathers and male family members in the community. Focusing on this group would aid our understanding of parents’ fears and expectations, also how they can be encouraged to use eating disorders services and how such services could best serve their needs.

- Further qualitative research with South Asian females is needed to understand why some drop out of therapy or others who may not take up the offer of therapy after assessment, in particular their fears and relationships with GPs and other health care professionals in terms of confidentiality. But also their beliefs about psychological therapies, how they work, and how this fits with their beliefs about their disorder. This would highlight gaps in service provision which can be improved to maximise service engagement from these groups of females. Related to this is the issue of effectiveness of
therapy for South Asian females, as at present NICE guidance (2004) exists on evidence largely based on Caucasian women, and therefore this cannot be generalised.

7.7 Recommendations

Based on the findings from this study the following recommendations (see Tables 23 & 24) can form the basis of training and professional’s development and empower professionals to engage with South Asian females and family members affected by Eating Disorders, enabling them to address the help these individuals need and plan support accordingly. The main aim is to find ways of overcoming the barriers in accessing services for this group raise awareness among the South Asian community around dating disorders and enhance cultural competence of health care professionals in interacting with South Asians with eating disorders.
<table>
<thead>
<tr>
<th>Barriers</th>
<th>Recommendations</th>
<th>Impacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents lack of Knowledge, understanding and recognition of the seriousness of ED</td>
<td>Accessible information on ED aimed at South Asian Community.</td>
<td>Availability of information on ED aimed at this population.</td>
</tr>
<tr>
<td>No language for ED in Urdu, Punjabi, Hindi or Salehti</td>
<td></td>
<td>Leaflets to be printed in most widely spoken community languages, a basic leaflet explaining exactly what ED are and where to go for help.</td>
</tr>
<tr>
<td>Fear of being seen – family shame, stigma of mental health, arrange marriage impact</td>
<td></td>
<td>These leaflets to be distributed at GP surgeries, community centres, local library, places of worship etc.</td>
</tr>
<tr>
<td>Fear of disclosing information Generation gap experienced by between parents and daughters</td>
<td>Community education programmes through:</td>
<td>Community level programmes aimed at the South Asian community may help in understand ED and might be useful in targeting the parents, husbands, and parent in-laws of such women as well as the women themselves, through talks by community figures/leaders/celebrities, within mosques, temples, community centres.</td>
</tr>
<tr>
<td></td>
<td>Community development projects</td>
<td>School curricula may also place more emphasis on mental health topics in particular eating disorders including the benefits of seeking help early on.</td>
</tr>
<tr>
<td></td>
<td>Religious bodies</td>
<td></td>
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<td></td>
<td>Outreach projects</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Schools and Youth work</td>
<td></td>
</tr>
<tr>
<td>Engagement with local Asian media</td>
<td>Work with radio and local TV channels e.g. talks on radio by professionals about ED and South Asian females. Publicise services through local radio, websites, magazines, newspapers that mainly focus on the South Asian population.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Information programmes that emphasise the health advantages of early detection and treatment of eating disorders could be beneficial.</td>
<td></td>
</tr>
<tr>
<td>Barriers</td>
<td>Recommendations</td>
<td>Impacts</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Health Care professionals not being aware of ED as a South Asian problem.</td>
<td>Recognising and diagnosing Assessment trust/ confidentiality</td>
<td>Cultural adaptation of Eating Disorder Services, including tools used for assessment.</td>
</tr>
<tr>
<td>Family member present during consultation</td>
<td>Appreciation of South Asian family and culture.</td>
<td>Raise awareness among health care professionals Cultural sensitivity.</td>
</tr>
<tr>
<td>Lack of trust and breach of confidentiality with health care professional.</td>
<td>SERVICES also need to understand how ideas of parenting and culture differ not only between ethnic groups but also between each sub-ethnic group.</td>
<td>Service delivery programs could place greater emphasis on the needs of South Asian females suffering from eating disorders and understanding the cultural issues they face. This will aid early diagnosis and treatment. A key area that needs to be improved is working to improve the public impression of GPs among communities and professional.</td>
</tr>
<tr>
<td>Fear of asking patient about ED symptoms as concern about cultural offending.</td>
<td>Programmes for voluntary and statutory sector</td>
<td>Involvement of South Asian voluntary groups in the planning of services.</td>
</tr>
<tr>
<td>Difficult to carry out a physical exam/identify ED on women in traditional dress.</td>
<td></td>
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<tr>
<td>Services providers’ lack of confidence in meeting needs of South Asian females with ED.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improving staff training</td>
<td></td>
<td>Involvement of local south Asian voluntary groups in planning cultural competence training. Encourage feedback from patients about their experience of services.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Work in collaboration, sharing expertise, partnership bids for funding and identify training needs and development.</td>
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<tr>
<td></td>
<td></td>
<td>Mapping of voluntary and statutory sector for ED services and identify gaps in provision for South Asian population</td>
</tr>
<tr>
<td>Family intervention</td>
<td></td>
<td>Family intervention that directly address ED should be offered to the patient and family (Separate or Conjoint)</td>
</tr>
</tbody>
</table>
7.8 Over all thesis summary and conclusion

This is the first systematic exploration of the experience of eating disorders among South Asian females. The work has revealed differences in prevalence of eating disorders between Caucasian and South Asian women, with greater levels of Eating Disorders amongst South Asian females than amongst Caucasians living in the UK, or than amongst South Asian in the Indian subcontinent. A systematic review of the literature revealed very limited research to explore reasons for this difference or attempts to understand South Asian women’s experience of Eating Disorders. Qualitative research presented within the thesis, with women, their families and healthcare professionals working in the field, revealed that family and cultural issues are viewed as being central to the development and maintenance of eating disorders in this population, and hinder their access to services. Findings suggest that in making sense of and coming to terms with family obligations and control, participants developed and maintained their dating disorders.

The current research aimed to understand the issues relating to the development, maintenance of eating disorders and help-seeking behaviour and barriers to assessing treatment for eating disorders among South Asian females, also family and cultural issues that might contribute to those barriers and maintenance or that facilitate treatment seeking recovery. In order to examine this, three studies were conducted; study 1 found that, overall the studies reviewed show that prevalence of diagnosable eating disorders was greater among South Asian females than among Caucasians living in the UK or among the South Asian living in the Indian subcontinent, in particular for bulimia. However the low quality of these studies in terms of their methodology means it is difficult to draw clear conclusions and findings made cannot be generalised beyond the higher Social Economic Status groups that were sampled. However these studies ascertain that South Asian females are far from immune to developing eating disorders and that the prevalence of Eating Disorders is increasing among these groups of women and that cultural factors seem to be important in the development and the maintenance Eating Disorders. A review of qualitative studies (Study 2) was conducted to explore the factors in the development and maintenance of Eating Disorders and to understand the higher prevalence levels found in study 1.
Although the reviewed studies were poor in terms of methodology, they did however, identify relevant themes pertaining to cultural conflict and controlling family. Thus, given the evidence that eating disorders is prevalent among South Asian women and the lack of qualitative research, a qualitative study was conducted to explore the perceptions and experiences of British South Asian females with dating disorders, family members and health care professionals. The principal aims were to increase understanding of the psychosocial factors that South Asian females with Eating Disorders perceive to be important in the development and maintenance of their Eating Disorders and the difficulties they experience in accessing services. This research seemed to suggest that the development and maintenance of unhealthy eating attitudes among South Asian females stems from the perceived family control and the effects of living in both Asian and Western cultures. South Asian females perceived a double pressure to be slim and beautiful, from both Eastern and Western culture. They also experienced high levels of cultural stress in terms of control by parents on important life choices like choice of life partner, career, and social life. They were also perceived to be treated as a ‘commodity’, in order to gain the best possible marriage proposal. The participants had conflicting pressures, from the Western pressure to be independent and from the Asian culture to be dependent. This resulted in a constant battle to comply with the demands of two distinct cultures, and these pressures did affect the women's eating habits as a form of internal control.

Mental illness has a severe negative connotation in South Asian culture. The fact that mental illness is believed to be prevalent in a family, especially that of an unmarried female, compounds the seriousness of this diagnosis because it can create problems of attracting a future marriage proposal. Shame and denial are typical responses to any suggestion of emotional illness. These responses are especially problematic when they block individuals from seeking help and result in only seeking help when the problem becomes severe. The present study highlights how South Asian females experiencing eating disorders may be unsupported and criticised by their families and the difficulties this can create for them.

South Asian females experience dual identity and there are problematic factors that impact on them, such as cultural and family pressure and expectations. These young
women have to deal with issues within and outside of the home environment and participants identified that culturally sensitive services need to be developed that address women’s emotional health and well-being. Above all, professionals need to develop an understanding of cultural and religious issues if these women’s needs are to be met. It may also be beneficial to encourage family therapy, as evidence which suggests it can work well, particularly if it helps the parent to understand the illness and the need to support their daughter appropriately and most importantly, to change their attitudes towards mental illness, in particular eating disorders. There is a need for health care professionals to understand and appreciate the complexities of the difficulties around family and culture young South Asian women encounter. Family relationships and dynamics need to be understood in the deference between first and second generation of South Asians, and their expectations based on the two conflicting cultures. The different pressures on different roles in school, at work and in the family across generations have been usefully described as ‘asynchronous acculturation’ (Khan & Waheed, 2009). As the study highlighted that initial assessments are not carried out or conducted properly, professionals must consider what information is collected during assessment, the tools utilised to do this and the importance of sensitive questioning.

The findings of the current research infers that despite a potentially rising prevalence, the clinical needs of this population are not being met and South Asian females need particular support to help them access and cope with the complex pressures perceived. In particular health care professionals need to optimize the quality of care they provide by developing relevant cultural competence. Knowledge of the cultural beliefs, attitudes, and experiences of these females and consideration of the patient’s stage in the acculturation process are all important in establishing rapport, identifying psychosocial needs and providing high-quality primary care. These factors need to be explored by health care professionals, as to what impact if any these are having on the psychological well-being of the individual, highlighting the need for training in this area. Important also is the need to establish trust and confidentiality between services and their users, from primary care through to secondary care. Furthermore, appropriate service development for young people from Asian communities requires their involvement in planning and implementation from the onset, rather than attempting to slot them into services that are not tailored
to meet their needs. Local authorities in areas with a significant South Asian population need to clearly identify the cultural and social needs of this group in developing health strategy and policy.
References


36. Bhui, K., & Shashidharan (2003), Should there be separate psychiatric services for ethnic minority groups? British Journal of Psychiatry, 18, 10-12


43. Bhopal, R. Glossary of terms relating to ethnicity and race : for reflection and debate. Epidemiol Community Health (2004); 58: 441-445


84. D’Alessio & Ghzi, 1993; Asian women in suicide epidemic. The Observer, P6


119. Goodchild S. Dying to be thin: Why one in 100 young women suffer from eating disorders. The Independent 29th October 2006.


223. movinghere.org.uk


http://guidance.nice.org.uk/


http://guidance.nice.org.uk/


237. Noblit, W,G & Hare R,D (1988), (Citation), Meta-ethnography: Synthesizing qualitative studies – sage


244. Observational Studies. PLOS Medicine. 2007; 4(10): 296-301


283. Shurique N. Eating Disorders – A transcultural perspective, Volume 5, issue 2, 1999, P 354-360


343. www.mind.org.uk

344. www.statistics.gov.uk


**Appendix 1: STROBE Statement—checklist of items that should be included in reports of observational studies**

<table>
<thead>
<tr>
<th>Item No</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title and abstract</strong></td>
<td></td>
</tr>
</tbody>
</table>
| 1 | *(a)* Indicate the study’s design with a commonly used term in the title or the abstract  
*(b)* Provide in the abstract an informative and balanced summary of what was done and what was found |
| **Introduction** | |
| 2 | Explain the scientific background and rationale for the investigation being reported |
| **Objectives** | |
| 3 | State specific objectives, including any prespecified hypotheses |
| **Methods** | |
| 4 | Present key elements of study design early in the paper |
| 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection |
| 6 | *(a) Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up  
*Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls  
*Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants  
*(b) Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed  
*Case-control study*—For matched studies, give matching criteria and the number of controls per case |
| 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable |
| 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group |
| **Bias** | |
| 9 | Describe any efforts to address potential sources of bias |
| **Study size** | |
| 10 | Explain how the study size was arrived at |
| **Quantitative variables** | |
| 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why |
| **Statistical methods** | |
| 12 | *(a) Describe all statistical methods, including those used to control for confounding  
(b) Describe any methods used to examine subgroups and interactions  
(c) Explain how missing data were addressed  
(d) Cohort study*—If applicable, explain how loss to follow-up was addressed |
Case-control study—If applicable, explain how matching of cases and controls was addressed

Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy

(e) Describe any sensitivity analyses

Results

Participants 13*

(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed

(b) Give reasons for non-participation at each stage

(c) Consider use of a flow diagram

Descriptive data 14*

(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders

(b) Indicate number of participants with missing data for each variable of interest

(c) Cohort study—Summarise follow-up time (eg, average and total amount)

Outcome data 15*

Cohort study—Report numbers of outcome events or summary measures over time

Case-control study—Report numbers in each exposure category, or summary measures of exposure

Cross-sectional study—Report numbers of outcome events or summary measures

Main results 16

(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included

(b) Report category boundaries when continuous variables were categorized

(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period

Other analyses 17

Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion

Key results 18

Summarise key results with reference to study objectives

Limitations 19

Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias

Interpretation 20

Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence

Generalisability 21

Discuss the generalisability (external validity) of the study results

Other information

Funding 22

Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.
Appendix 2: Critical Appraisal Skills Programme (CASP)

Making sense of evidence

10 questions to help you make sense of qualitative research

This assessment tool has been developed for those unfamiliar with qualitative research and its theoretical perspectives. This tool presents a number of questions that deal very broadly with some of the principles or assumptions that characterise qualitative research. It is not a definitive guide and extensive further reading is recommended.

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of qualitative research:

• Rigour: has a thorough and appropriate approach been applied to key research methods in the study?
• Credibility: are the findings well-presented and meaningful?
• Relevance: how useful are the findings to you and your organisation?

The 10 questions on the following pages are designed to help you think about these issues systematically.

The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

The 10 questions have been developed by the national CASP collaboration for qualitative methodologies.

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Screening Questions

1. Was there a clear statement of the aims of the research? □ Yes □ No
   
   Consider:
   – what the goal of the research was
   – why it is important
   – its relevance

2. Is a qualitative methodology appropriate? □ Yes □ No
   
   Consider:
   – if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

   __________

   Is it worth continuing?
   
   Detailed questions

   ……………………………………………………………………………………………

   Appropriate research design

3. Was the research design appropriate to address the aims of the research? Write comments here
   
   Consider:
   – if the researcher has justified the research design
     (e.g. have they discussed how they decided which methods to use?)

   ……………………………………………………………………………………………

   Sampling

4. Was the recruitment strategy appropriate to the aims of the research?
   
   Consider:
   – if the researcher has explained how the participants were selected
   – if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
   – if there are any discussions around recruitment (e.g. why some people chose not to take part)

   Data collection

5. Were the data collected in a way that addressed the research issue? Write comments here
Consider:

– if the setting for data collection was justified
– if it is clear how data were collected
  (e.g. focus group, semi-structured interview etc)
– if the researcher has justified the methods chosen
– if the researcher has made the methods explicit
  (e.g. for interview method, is there an indication
  of how interviews were conducted, did they used a topic guide?)
– if methods were modified during the study.
If so, has the researcher explained how and why?
– if the form of data is clear (e.g. tape recordings, video material, notes etc)
– if the researcher has discussed saturation of data

Reflexivity

( research partnership relations/recognition of researcher bias)

6. Has the relationship between researcher and participants been adequately considered?

Consider whether it is clear:
– if the researcher critically examined their
  own role, potential bias and influence during:
  – formulation of research questions
  – data collection, including sample recruitment and
    choice of location
  – how the researcher responded to events
    during the study and whether they considered the
    implications of any changes in the research design

Ethical Issues

7. Have ethical issues been taken into consideration? Write comments here

Consider:

– if there are sufficient details of how the research
  was explained to participants for the reader to
  assess whether ethical standards were maintained
– if the researcher has discussed issues raised
  by the study (e.g. issues around informed consent
  or confidentiality or how they have handled the
  effects of the study on the participants during and after the study)
– if approval has been sought from the ethics Committee

Data Analysis

294
8. Was the data analysis sufficiently rigorous? Write comments here

Consider:
– if there is an in-depth description of the analysis process
– if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
– whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
– if sufficient data are presented to support the findings
– to what extent contradictory data are taken into account
– whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Findings

9. Is there a clear statement of findings? Write comments here

Consider:
– if the findings are explicit
– if there is adequate discussion of the evidence both for and against the researcher’s arguments
– if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)
– if the findings are discussed in relation to the original research questions

Value of the research

10. How valuable is the research? Write comments here

Consider:
– if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
– if they identify new areas where research is necessary
– if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used
### Appendix 3: Quality Appraisal Checklist (Walsh & Downe, 2006)

#### Summary criteria for appraising qualitative research methods

<table>
<thead>
<tr>
<th>Stages</th>
<th>Essential criteria</th>
<th>Specific prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scope and purpose</strong></td>
<td>Clear statement of, and rationale for, research questions/aims/purpose</td>
<td>• Clarity of focus demonstrated</td>
</tr>
<tr>
<td></td>
<td>Study thoroughly contextualised by exiting literature</td>
<td>• Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Link between research and existing knowledge demonstrated</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both</td>
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<td><strong>Design</strong></td>
<td>Method/design apparent, and consistent with research intent</td>
<td>• Rationale given for use of qualitative design</td>
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<td>• Discussion of epistemological/ontological grounding</td>
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<td>• Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology)</td>
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<td>• Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims</td>
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<td>• Were data collection methods appropriate for type of data required and for specific qualitative method? Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?</td>
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<td>• Was triangulation of data sources used if appropriate?</td>
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<td>Sampling strategy</td>
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<td>• Selection criteria detailed, and description of how sampling was undertaken</td>
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<td>• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory)</td>
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<td>• Was it appropriate for the qualitative method chosen?</td>
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<td>• Evidence that the subjective meanings of participants were portrayed</td>
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<td>• Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance</td>
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<td>• Did research participants have any involvement in analysis (e.g. member checking)</td>
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<td>• Evidence provided that data reached saturation or discussion/rationale if it did not</td>
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<td>• Evidence that deviant data was sought, or discussion/rationale if it was not</td>
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<td>• Description of social/physical and interpersonal contexts of data collection</td>
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<td>• Evidence that researcher spent time ‘dwelling with the data’, interrogating it for competing/alternative explanations of phenomena</td>
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<td>Significance for current policy and practice outlined</td>
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<td>Assessment of value/empowerment for participants</td>
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<td>Outlines further directions for investigation</td>
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<td>Comment on whether aims/purposes of research were achieved</td>
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Appendix

"I am facing what is called 'culture clash'. Because I have been educated in England I have been taught to be independent, original, to think for myself and to be successful in my life by achieving what I aim for. In school I was prepared how to handle my life and how to stand up for myself, while when I went home I was expected to be quiet, submissive, obedient and totally dependent on my parents.

"Like most Asian parents, my parents believe that only they know what is best for me. That is why they find it hard to cope with me not being happy with their decision about my marriage. My parents see the breakdown of my marriage as totally my fault. They believe girls should not speak up and should let their parents decide what happens in their life. Asian culture has a lot of influence over how older people think and it is because of the culture that I am expected to sacrifice my life and happiness for the sake of my parents and family's honour and respect.

"My parents treat me as if I have been a big failure to them - I am seen as unworthy and unreliable and get treated as if I am a rebel. It is hard enough for me to make a decision on what I am going to do in the future without the added burden of thinking of the family and their images. I feel trapped most of the time anyway, because no matter what I do I will end up losing in one way or another. I know I am caught in the 'Catch-22' situation. If I do as my parents ask I will lose out on my own life and if I do as I please I would probably lose my family. I do not know why I should do as the parents and family ask - they have all enjoyed their lives and now they want to control my life.

"There are times when I fell really guilty about causing all this trouble. I feel weighed down and depressed most of the time and the only way I can pick myself up is by thinking of how I would like things to be or how far I would have got in five years' time... I will never give in to them though: there is no way I can live under their thumb. I do not know where I stand with my family and relatives; I feel confused when my relatives are around, but I have still got some fight left in me yet."
Appendix 5: Interview schedule – ED participant

Interview Schedule for person who has experienced an eating disorder

1. Opening
Questions may alter in accordance to how the interview proceeds.

**Clarify ethical implications, confidentiality, and consent**
Ensure that participants have read and signed the consent form. Emphasise that the data from the interview will be treated in a confidential manner, which they can stop at any point without negative consequence, and ask them if they have any questions.

**Explain the aims of the research**
I’d like to find out about your understanding and experiences of eating disorders, what you consider to have contributed to your disorder and how you cope with it and what your experiences are of accessing services.

2. Experience of having an eating disorder.
Explore their experiences and perceptions of having an eating disorder.
- When do you think you first recognised that you had eating problems? (How and why do you think it started?)
- How long have you had it? Describe your typical day?
- How do you cope and manage with your disorder and how does it make you feel?
- What do you think your families concerns are?
- How did they react when they found out?

3. Experiences of accessing services.
Encourage the participant to provide a descriptive overview of the services that they received. Encourage the participant to explore their opinions about the strengths and weaknesses of the service.

I. Format
How did you hear about the service/Who referred you to the service?
What did you do?
Did the sessions change over time or was each one much the same as the rest?
Are you satisfied with what you were offered?

II. Delivery
What did you think of their approach?
In your opinion what do think would help you recover from your disorder?
How long have you been using this service?

III. Time
How did you find the length of each session?
How often were they? (Was that frequent enough/not frequent enough?)
Were you happy with the number of sessions overall?

IV. Location
Where did the sessions take place?
Was it easy to get to?
Did you require any special travel arrangements?

4. Closing
Is there anything that you would have liked me to ask about but I didn’t? Do you have any further suggestions for how the services could be improved in the future?
Interview Schedule for Parent/Sibling

1. Opening
Questions may alter in accordance to how the interview proceeds.
**Clarify ethical implications, confidentiality, and consent**
Ensure that participants have read and signed the consent form. Emphasise that the data from the interview will be treated in a confidential manner, which they can stop at any point without negative consequence, and ask them if they have any questions.

2. **Explain the purpose of the interview and highlight the areas to be covered.**
I would like to find out about your understanding of eating disorders. What’s it like to live or take care of a family member with an eating disorder.

Explore their experiences and perceptions about eating disorders and living with or having a family member with an eating disorder.

- What are you views about eating disorders?
- How did you first find out that your daughter/sister had an eating disorder?
- How did you feel?

3. Experience of living with someone who has an eating disorder
Encourage the family member to provide a descriptive overview of the services they have accessed and explore their opinions about the strengths and weaknesses of the service.

How did you hear about the service? Who referred you?
Can you describe the treatments given and for how long?
In your opinion was this helpful? How?
In your opinion was the service provider able to meet the needs of your daughter/sister?
In your opinion how can these services be improved?
How do you think services that you have been offered has had an effect on you personally (positive/negative)?

4. Closing
Is there anything that you’d of liked me to ask about but I didn’t? Do you have any further suggestions for how the services could be improved in the future?
Appendix 7- Interview Schedule & questions – Health Care Professional

Interview Schedule for Health professional

1. Opening
Questions may alter in accordance to how the interview proceeds.
**Clarify ethical implications, confidentiality, and consent**
Ensure that participants have read and signed the consent form. Emphasise that the data from the interview will be treated in a confidential manner, which they can stop at any point without negative consequence, and ask them if they have any questions.

2. Explain the purpose of the interview and highlight the areas to be covered
I would like to find out about your understanding of eating disorders and experiences of providing services to individuals in particular Asian females of Pakistani, Bangladeshi or/ and Indian ethnicity with eating disorders.

3. Experience of providing services to those who have an eating disorder.
Explore their experiences and perceptions of working for mental health services in particular providing services to individuals with eating disorders.
- How long have you worked in this post?
- What training have you received?
- How confident do you feel about delivering this service to young South Asian females?
- Have ever had cultural awareness/competence training?

Encourage the provider to provide a descriptive overview of the services they provide and explore their opinions about the strengths and weaknesses of the services.
In your opinion what is in place to meet the needs of South Asian females with an eating disorder?
Do you work in partnership with any other organisation? If yes how and at what stage?
How do you raise awareness amongst the South Asian community about your services?
Do you feel you have enough support and training to help provide a service for south Asian females? If yes describe/ if no then what can help you?
Have or any other member of staff you know provided advice/service for South Asian females with an eating disorder.

4. Closing
Is there anything that you’d of liked me to ask about but I didn’t? Do you have any further suggestions for how the services could be improved in the future?
Appendix 8: Eating Disorder Examination Questionnaire (EDEQ)

EATING DISORDER EXAMINATION QUESTIONNAIRE - "EDE-Q"

Introduction
The EDE-Q is a self-report version of the Eating Disorder Examination, the well-established investigator-based interview (Fairburn and Cooper, 1993). It is scored in the same way as the EDE. Its performance has been compared with that of the EDE: in some respects it performs well, but in others it does not (see papers below).

Investigators are welcome to use the EDE-Q free of charge on three conditions:
1. It is understood that it is an instrument in evolution rather than a final version.
2. It is understood that it is under copyright.
3. In any publication the following citation is used for the instrument:


Scoring
The EDE and EDE-Q generate two types of data. First, they provide frequency data on key behavioural features of eating disorders in terms of number of episodes of the behaviour and in some instances number of days on which the behaviour has occurred. Second, they provide subscale scores reflecting the severity of aspects of the psychopathology of eating disorders. The subscales are Restraint, Eating Concern, Shape Concern and Weight Concern. To obtain a particular subscale score, the ratings for the relevant items (listed below) are added together and the sum divided by the total number of items forming the subscale. If ratings are only available on some items, a score may nevertheless be obtained by dividing the resulting total by the number of rated items so long as more than half the items have been rated. To obtain an overall or 'global' score, the four subscales scores are summed and the resulting total divided by the number of subscales (i.e. four). Subscale scores are reported as means and standard deviations.

Subscale Items:
Restraint
1 Restraint over eating
2 Avoidance of eating
3 Food avoidance
4 Dietary Rules
5 Empty stomach

Eating concern
6 Preoccupation with food, eating or calories
7 Fear of losing control over eating
8 Eating in secret
9 Social eating
10 Guilt about eating

Shape concern
11 Flat stomach
Appendix 9: Dairy of recruiting participants

Stage 1.

Sending out information about the research

Concentrated mostly on high South Asian populated areas to make sure the right community was targeted, but also wanted to recruit through well-established websites.

BEAT agreed to display the research poster on their website for the duration of the research project. So far have not been able to recruit through this, but have had some interest from research students who wanted to know more about the research.

Letter detailing the study and recruitment poster was sent by post to GP’s, mental health services, colleges and universities in the following areas:
- Tameside and Glossop
- Manchester
- Bolton
- Oldham
- Salford
- Rochdale

After a week the researcher contacted the different organisations and services by phone to ask if they had decided to take part in the study. Not one Gp surgery contacted or wanted to take part in the study.

Mind centres around greater Manchester were called and sent information about the research most of them had not come across Asian females with eating disorders.

Eg on 26 January 2012, a Gp responded to my request of taking part in the study: “In this small town (Rochdale) we have but few patients who fit the bill. I know the handful of such young women and none have an eating disorder either too little or too much. Therefore I shall decline the invitation to participate in the study”.

Looked at tapping into existing women’s group and talk about the research:

- Manchester women’s aid group in (Name of place) - visited on 17th January 2012 at 1.30pm
- (Name of person) group at MCCR - due to visit 7th March 2012 at 12.00
- Community groups in (Town), have been identified need to set up visit.

Wanted to have a range of individuals to interview under professionals, looked at community workers, counsellors and Gp’s:
Stage 2

Setting up interviews

1. Made a random phone call, female community worker agreed to be interviewed.
   6th October 2011 @ 10.30am, Community worker, (Name of place and town).

2. Made a call to (Town) Mind centre, talked to worker about the research she agreed to be interviewed. After the interview she gave me contact details of a female counsellor who worked with young Asian females in ((Town)and community worker of another project in the area.
   21st October 2011 @ 10.30am, Community worker Mind wellbeing centre (Town).

3. Received a call from a young Asian female, asked if she can take part in the study, had been suffering from eating disorders since she was 13. She had come across research poster at the Mind centre in Rochdale.
   21 years old South Asian female with eating disorder, interviewed at the University of (City) @ 11.30am.

4. 15th November 2011 @ 2.30pm, community worker at (Town)women’s association, after the interview suggested I talk about the research on the local radio station (need to set this up).

5. 2nd December 2011 @ 11am, Asian female counsellor, (Place & Town). Found it difficult to get hold of her, managed to get her attention by emailing research details. She contacted me by phone to set up meeting.

6. Random call, talked about the research and set up date for interview. 11th January 2012 @ 10.15am senior outreach worker, (City) Women’s aid, (organisation).

7. Contacted the Mind centre and the Drugs and Alcohol team in (Town), directed to the team in (Organisation). Difficult at first to set up this interview managed to get a response from an Asian female community worker. Interview took place on the 2nd of March 2012 at 2.30pm in (Town). After the interview I was given a contact of a Gp who may be interested in taking part in the study from the (Organisation), (Town) (need to contact).

8. 7th March 2012, need to think how to recruit parents, contacted an Asian women’s group. Was invited to give a talk about the research on the 20th of March 2012 at 11.30am, MCCR. Another group for the 21st of March 2012 at 12-00, (Town) community centre. Main aim to highlight the issues around eating disorders but also to recruit parents/ siblings.

9. 20th March 2012 at MCCR Meeting with an Asian women’s community group predominantly Pakistani aged between 50 and 70. None of the group members were aware of the term eating disorders and were shocked to hear its prevalence among young Asian females. No potential participants

10. 21st March 2012 at (Town) community centre, - Meeting with an Asian women’s community group predominantly Pakistani aged between 50 and 70. None of the group members were aware of the term eating disorders and were shocked to hear its prevalence among young Asian females. No potential participants.
11. 23rd of March – attended a “Bollywood night” just for women at the (Place) at 6.00pm. Distributed research flyers and talked to different members of the different organisation present.

12. 26th March 2012 - Interview with community protect officer at the (Place) at 10.30. Good interview but no referrals.

13. 27th March 2012 at 9.30am- interview with student counsellor based at the (name of college). No referrals.

14. 17th April 2012, at 10.30am- Interview with a sibling (sister) – interesting but afraid to talk to the rest of the family about it – no referral.

15. 19th April 2012 at 10.00am- Interview with participant diagnosed with eating disorders, had cancelled twice previously agreed to meet at her place of residence. Participant very emotional during the interview, but was happy to continue. Was not happy for the family to be contacted to take part in the research.

5.00 pm in (Town)- Interview with Participant diagnosed with eating disorders, agreed to meet at a neighbour’s house did not want the family to know about the interview.

16. 21st April 2012 – 10.30am interview with a sibling (sister) – did not want to talk to her sister about the research.

17. 16th May 2012- 11.00am interview with a professional at (Place), (City). No referrals.

18. 25th May 2012 (Town) – 1.00pm Interview with a professional (Gp and clinical lead for mental health)- No referrals disappointingly.

19. 29th May 2012 – 4.00pm Interview with a counsellor based at the Roby – no referrals.

20. 21st June 2012 – Decided to take flyers and distribute in and around (Town), (City). Visited schools and projects. Through the Sure Start Centre managed to set up interview with a sibling (sister) for the following day.

21. 22nd June 2012- 11.45- (School) (Town) – Interview with sibling (sister). Did not want the sister with the disorders contacted.

22. 22nd June 2012 – contacted by a potential participant saw the advert on the University website, organised to meet on the 27th of June 2012.

23. 27th June 2012- 2.15pm interview with participant (medical student) diagnosed with anorexia but receiving no treatment. Interview took place at the University of (City) in a meeting room. Did not want the family to be contacted.

24. 2nd July 2012 – 3.45pm interview with a participant diagnosed with Anorexia, not receiving treatment. Interview took place in the participants’ car! Separated from husband for about a year has two boys under the age of 10yrs. Resident in the UK for the last three years. Did not have any family to contact.

25. 29th October 2012- 12.30 visited (Place) to meet a community group aged between 30 and 70. Raised awareness about eating disorders but no potential participants. Also contacted (Town) healthy Living Project and emailed information about the research.

26. 6th November 2012 – 10.30 meeting with the (Town) Bangladeshi Welfare group in (Town)- Asian women’s group with mental health issues, again not aware of eating disorders nor it’s prevalence amongst Asian females. No referrals.
27. 8th November 2012- (City)- Contacted (name of hospital) and counselling services based at the University of (City). Emailed Information about the research. Also contacted the
28. 12th November 2012- Sent email to (Name), (City) counselling services. At 11.00am Interview at (Town) PCT Centre with a female youth worker coordinator, works with young Asian females aged between 16 and 20. No referrals.
29. 14th November 2012 – 12.00 interview with mother of a teenager with an eating disorder. She is a part-time health worker at a local community project. Could not interview daughter too young.
30. 16th November 2012- 11.00am meeting a bangladeshi women’s group aged between 20 and 60yrs at sure start (Town). Talked about eating disorders most did not understand the term but were again alarmed that this is prevalent in young Asian females. I was not expecting any one to fit the criteria but I was approached by a mother and a female community worker diagnosed with anorexia wanted to take part in the research.
31. 22nd November 2012- 6.00pm attending an AGM meeting at the Village hotel in (Town) to distribute research flyer. A bit disappointed very few attendants because of the weather. But made some good contacts.
32. 27th November 2012- (City)- 11.00am interview with a Bangali participant diagnosed with anorexia – community worker. Did not want the family to be contacted. 12.00am interview with a Bengali mother desperate to find answers about her teenage daughter being severely underweight – did not know about the term eating disorders.
33. 28th November 2012- Gaskell House, (City), 9.00am Interview with a Caucasian male psychoanalytic psychotherapist. Has worked with Asian females diagnosed with eating disorders. Two referrals!
34. 3rd December 2012- (Name of hospital), (City), 1pm interview with an Indian lead consultant psychiatrist eating disorders. Very busy with patients on the ward has treated very sick Asian females as a result of eating disorders. Too busy to finish full interview and arranged for a telephone interview on the 5th of December.
35. 5th December 2012 – 12.00noon telephone interview with consultant psychiatrist. Did refer but no past or present patients’ interested.
36. 6th December 2012 – 3.00pm interview with an overseas masters student from Pakistan. Elite background I Pakistan very westernized. Diagnosed with anorexia but not receiving treatment. Family not interested.
37. 7th December 2012- 10.30 am (Town), interview with Asian male consultant psychiatrist. Reluctant to be tape recorded put agreed. No referrals.
38. 14th December 2012- 6.00pm in (Town), meeting with young Asian females group aged between 16 and 20yrs. Aware of eating disorders but not in Asian females. No referrals.
39. 17th December 2012- 11.30am meeting with Caucasian female counsellor, has worked in a clinical setting with young Asian females around mental health and family issues. No referrals.
40. **18th December 2012** - Booked out the whole day to visit community projects, Gp surgeries and sure start centres to distribute research flyer within (Town)-u-Lyne.

41. **19th December 2012** - Booked out the whole day to visit community projects, Gp surgeries and sure start centres to distribute research flyer within (Town).

42. **20th December 2012** - Booked out the whole day to visit community projects, Gp surgeries and sure start centres to distribute research flyer within (Town)-u-Lyne.

43. **24th January 2013** - 2.00pm interview with a retired Indian nurse after two failed attempts. 64yrs old diagnosed with anorexia and bulimia receiving counselling. Husband not understanding, grown up daughters and son. Daughters very supportive. Currently an inpatient at Cheedle royal.

44. **4th February 2013** – 11.30 am interview with Indian female diagnosed with anorexia receiving counselling. Very emotional during the interview particularly when talking about her mother. Parents separated when she was very young. Interview took place within The University of (City).

45. **5th February 2013** – 2.00pm interview with a young Asian male Gp and clinical lead – Hulme (City). Very interested in the subject area and forward contacts of other Gps. No referrals.

46. **19th February 2013** - meeting with an Asian female worker at the new charter academy, works with Asian parents and young Asian female students. No referrals.

During the visit talked to a young Asian female parent about the research, she was interested in taking part and suggested that I also talked to her daughter who has been suffering from severe weight loss. Her daughter rang that evening to set up an interview.

47. **20th February 2013** - 11.00am interview with 18 year old Asian female student severely underweight – anorexia not receiving treatment. Unhappy with gp, not referred her to a specialist, not weighed her. She also seemed to have a very “I don’t care approach” to her illness. Suffering from – no monthly periods, easily bruised and very fragile. Agreed for her mother to be interviewed.

48. **26th February 2013** - 11.00am (Town), interviewed Asian female mother, very concerned for her 18 year old daughter particularly about her weight. Angry with GP for not doing enough with be going to see him the following week.

49. **27th February 2013** - 12.00am (Town), interview with a Bengali sibling (sister) talked about her sister in great detail has been diagnosed with anorexia. Did not want sister to be interviewed.

50. **8th March 2013** - 10.00am 2nd interview with an Asian female first interviewed on the 1st of November 2012. Has since left home because of lack of support from family and services. Suffering from major health problems as well as mental, no employment low finance availability.

51. **14th March 2013** - 1.30pm Interview with Gp, very interested the subject area admitted that eating disorders is not something that you look for within Asian female patients. Need to be more aware and look out for the signs.
52. 17th April 2013- 12.00 noon meeting with an Asian women’s group (aged between 20 and 65 yrs) based in (Town) (City). Again no knowledge of eating disorders among young Asian females. No referrals.
Appendix 10: Letter to health care professionals

Date
Dear Dr

Improving understanding and access to treatment for eating disorders among young British South Asian females: a qualitative study
We are writing to invite your practice/organization to participate in this study that is being carried out in Greater Manchester. The aim of the research is to gain a better understanding of eating disorders among British South Asian females of Pakistani, Bangladeshi or Indian origin.
We would like to ask if you would be willing to participate in this study by any or all of:

1. Helping us to recruit young women between the ages of 16 and 25 from a South Asian background who would be willing to be interviewed.
2. Similarly helping us to approach family members to interview
3. Agreeing to be interviewed yourself about this issue
4. Displaying a poster on your waiting room noticeboard.

The project has received ethical approval from……………..and is funded by Liverpool Primary Care Trust as a PhD project.

We will follow up this letter with a telephone call to arrange to discuss this further and provide more information if you are interested in participating.

If you require any further information about the study please contact Bushra Nazir on 0161 275 6953 or 07896268183

Yours Sincerely

Linda Gask, Carolyn Chew-Graham
Professor of Primary Care Psychiatry Professor of Primary Care Psychiatry
University of Manchester University of Manchester
Appendix 11: poster advertising the study

Do you have an eating disorder?
Are you aged between 16-25?

Are you a British South Asian female of Pakistani, Indian or Bangladeshi origin?

We would like to learn and understand from you how eating disorders affect your life and how you manage and cope with it so that we can improve services for South Asian females with eating disorders. This research is funded by the NHS and is independent of any commercial interests.

If you would like to be interviewed to express your views or if you would like to find out more please contact Bushra at the University of Manchester on:

Tel: 0161 275 6953
Mobile: 07896268183
Email: bushra.nazir@postgrad.manchester.ac.uk

We will arrange to see you at a time and place that is convenient and can come to your home. If you prefer to come to us we will pay your travelling expenses.

We hope to hear from you soon.
Appendix 12: Letter from health care inviting potential participants

Letter head
Letter from GP/ Health Care Trust/ Hospital

Dear

At this surgery/health care trust/hospital we have decided to take part in a research study which I think may be of interest to you. It is confidential and nothing that you say will be shared with anyone, including your GP or other health professional. The study is interested in the understanding of eating disorders among British South Asian females of Pakistani, Bangladeshi or Indian origin. This is explained in the information sheet that comes with this letter. I would ask you to take the time to read this and consider if this would be right for you.

As stated in the information sheet, if you would like to talk to someone about this, or if you have any questions, you can ring the number listed or return the ‘Permission for researcher to contact’ form and send it free post to the address given.

In the next week or so one of the team here will give you a call to check that you have received this letter and to ask if you are interested. If you are certain that you do not want to take part in the study you may return the slip at the bottom of this letter and you will not be contacted again.

Thank you for taking the time to read this letter.

Yours sincerely,

Doctor’s name

I DO NOT want to take part in this study and DO NOT want a follow-up call

Name:

Signature:

Please return to us at the address above.
Appendix 13: Information sheet - ED participant

INFORMATION SHEET for participant

1. Title of the project: Improving understanding and access to treatment for eating disorders among young British South Asian females: a qualitative study.

2. Invitation
I am interested in understanding the issues relating to help seeking and barriers to access to treatment for British South Asian females with eating disorders. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and ask me if there is anything that is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part in the study.

3. The purpose of the study
The purpose of the study is to gain a better understanding of eating disorders among South Asian females of Pakistani, Bangladeshi or Indian origin.

4. Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and by filling out the form attached, the participant consent form. Should you wish to withdraw during the programme this can be done in writing or verbally at any time without any given reason.

5. What will I have to do if I take part?
You will be interviewed on one occasion by a researcher and the interview will be conducted at a time and place of your choosing. The duration of the interview will be approximately 45 minutes and, with your permission, will be audio recorded. During the interview you will be asked a range of different questions about your experience of having an eating disorder, the symptoms and problems that you have experienced, and your experience of accessing services. The interview will then be transcribed within six months, and the recording deleted. The transcribed interview, along with those of other participants, will be analysed to see what common themes emerge.

6. Are there any risks involved in taking part in the study?
We do not foresee any risks to you from taking part in the study. You will be free to disclose as much or as little as you wish.

7. Will there be any benefits to taking part in the study?
There are no direct benefits to you in taking part in the study. However, we anticipate that, by accurately describing experiences of Asian females with eating disorders, will provide valuable information for researchers and service providers that will ultimately be used to improve services.
8. Will my taking part in this study be kept confidential?
The information which we collect from the interviews will remain confidential within the study team and will not be discussed with or shown to anyone outside of the team without your written consent including your GP. Any identifying information (e.g. your name, place of work) will be removed from the transcripts before analysis occurs.

9. What will happen to the results of the research study?
We would aim to disseminate our findings through academic channels, such as conferences and publications. Your name will not be used in any publications or other modes of dissemination. If necessary, details will be changed to preserve your anonymity.

10. Who is organising and funding the research?
This research is being carried out by a PhD student at the University of Manchester and is being paid for by Liverpool Primary Care Trust.

11. Who has reviewed this study?
This study has been reviewed by ……………. Research Ethics Committee.

12. Contact for further information
If you need more information before you decide whether to take part, or if you have any questions which you want to ask, you can contact me via post, telephone, fax or email using the contact details given below:
Bushra Nazir  School of Medicine, Williamson Building, University of Manchester, Oxford Road, Manchester, M13 9PL. Tel: 0161275-56953
e-mail: bushra.nazir@postgrad.manchester.ac.uk

Thank you for taking the time to read this information sheet.
Appendix 14: Parent/ Sibling information sheet

INFORMATION SHEET for Family member/carer
1. Title of the project: Improving understanding and access to treatment for eating disorders among young British South Asian females: a qualitative study.

2. Invitation
I am interested in the perceptions and understanding of family members about service provision for eating disorders aimed at British South Asian females and experiences of taking care of a family member with an eating disorder. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and ask me if there is anything that is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part in the study.

3. The purpose of the study
The purpose of the study is to gain a better understanding of eating disorders among South Asian females of Pakistani, Bangladeshi or Indian Origin.

4. Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and by filling out the form attached, the participant consent form. Should you wish to withdraw during the programme this can be done in writing or verbally at any time without any given reason.

5. What will I have to do if I take part?
You will be interviewed on one occasion by a researcher and the interview will be conducted at a time and place of your choosing. The duration of the interview will be approximately 45 minutes and, with your permission, will be audio recorded. During the interview you will be asked about your experience of service provision for eating disorders aimed at British South Asian females and experiences of taking care of a family member with an eating disorder. The interview will then be transcribed within six months, and the recording deleted. The transcribed interview, along with those of other participants, will be analysed to see what common themes emerge.

6. Are there any risks involved in taking part in the study?
We do not foresee any risks to you from taking part in the study. You will be free to disclose as much or as little as you wish.

7. Will there be any benefits to taking part in the study?
There are no direct benefits to you in taking part in the study. However, we anticipate that, by accurately describing experiences of family members living or caring for someone with eating disorders, we will provide valuable information for researchers and service providers that will ultimately be used to improve services.

8. Will my taking part in this study be kept confidential?
The information which we collect from the interviews will remain confidential within the study team and will not be discussed with or shown to anyone outside of
the team without your written consent. Any identifying information (e.g. your name or place of work you mention) will be removed from the transcripts before analysis occurs.

9. What will happen to the results of the research study?
We would aim to disseminate findings through academic channels, such as conferences and publications. Your name will not be used in any publications or other modes of dissemination. If necessary, details will be changed to preserve your anonymity and that of any patients or colleagues you may mention.

10. Who is organising and funding the research?
This research is being carried out by staff at the University of Manchester and is being paid for by Liverpool Primary Care Trust.

11. Who has reviewed this study?
This study has been reviewed by……………….. Research Ethics Committee.

12. Contact for further information
If you need more information before you decide whether to take part, or if you have any questions which you want to ask, you can contact us via post, telephone, fax or email using the contact details given below:

Bushra Nazir  School of Medicine, Williamson Building, University of Manchester, Oxford Road, Manchester, M13 9PL. Tel: 0161275-56953
email: bushra.nazir@postgrad.manchester.ac.uk

Thank you for taking the time to read this information sheet.
Appendix 15: Consent form - ED participant

Improving understanding and access to treatment for eating disorders among young British South Asian females: a qualitative study.

Consent Form

Please initial each box

1) I confirm that I have read and understood the Participant Information Sheet

2) I understand that my participation is entirely voluntary and that I am free to withdraw at any time without my medical or legal rights being affected.

3) I understand that if I will withdraw from the study, information collected up to the point of my withdrawal will still be used

3) I agree to take part in the above study.

4) If I am invited to take part in an interview, I am willing for the interview to be recorded and transcribed.

5) If I am invited to take part in an interview, I am willing for anonymised direct quotations to be used in research presentations and publications

_________________ _____________ ______________
Name of Participant Date Signature

_________________ _____________ ______________
Name of Researcher Date Signature


Appendix 16: Consent form – Parent / Sibling

Improving understanding and access to treatment for eating disorders among young British South Asian females: a qualitative study.

Consent Form

Please initial each box

6) I confirm that I have read and understood the Participant Information Sheet.

7) I understand that my participation is entirely voluntary and that I am free to withdraw at any time without my legal rights being affected.

3) I understand that if I will withdraw from the study, information collected up to the point of my withdrawal will still be used.

4) I am willing for the interview to be recorded and transcribed, also for anonymised direct quotations to be used in research presentations and publications.

_________________________  ____________________  ____________________
Name of Participant          Date                      Signature

_________________________  ____________________  ____________________
Name of Researcher           Date                      Signature
Appendix 17- Information sheet – Health Care Professional

INFORMATION SHEET - Health Professional

1. Title of the project: Improving understanding and access to treatment for eating disorders among young British South Asian females: a qualitative study.

2. Invitation
I am interested in the perceptions and experiences of service providers in relation to British South Asian females of Pakistani, Bangladeshi or Indian ethnicity with eating disorders. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and ask me if there is anything that is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part in the study.

3. The purpose of the study
The purpose of the study is to gain a better understanding of eating disorders among South Asian females Pakistani, Bangladeshi or Indian ethnicity.

4. Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and by filling out the form attached, the participant consent form. Should you wish to withdraw during the programme this can be done in writing or verbally at any time without any given reason.

5. What will I have to do if I take part?
You will be interviewed on one occasion by the researcher and the interview will be conducted at a time and place of your choosing. The duration of the interview will be approximately 45 minutes and, with your permission, will be audio recorded. During the interview you will be asked about your experience of providing services to British South Asian females who have an eating disorder. The interview will then be transcribed within six months, and the recording deleted. The transcribed interview, along with those of other participants, will be analysed see what common themes emerge.

6. Are there any risks involved in taking part in the study?
We do not foresee any risks to you or your patients from taking part in the study. You will be free to disclose as much or as little as you wish.

7. Will there be any benefits to taking part in the study?
There are no direct benefits to you in taking part in the study. However, we anticipate that, by accurately describing experiences of service providers, we will provide valuable information for researchers and service that will ultimately be used to improve services.
8. Will my taking part in this study be kept confidential?
The information which we collect from the interviews will remain confidential within the study team and will not be discussed with or shown to anyone outside of the team without your written consent. Any identifying information (e.g. your name, place of work, or that of any patient or colleague you mention) will be removed from the transcripts before analysis occurs.

9. What will happen to the results of the research study?
We would aim to disseminate the findings through academic channels, such as conferences and publications. Your name will not be used in any publications or other modes of dissemination. If necessary, details will be changed to preserve your anonymity and that of any patients or colleagues you may mention.

10. Who is organising and funding the research?
This research is being carried out by staff at the University of Manchester and is being paid for by Liverpool Primary Care Trust.

11. Who has reviewed this study?
This study has been reviewed by the …………….Research Ethics Committee.

12. Contact for further information
If you need more information before you decide whether to take part, or if you have any questions which you want to ask, you can contact me via post, telephone, fax or email using the contact details given below:

Bushra Nazir  School of Medicine, Williamson  Building, University of Manchester, Oxford Road, Manchester, M13 9PL. Tel: 0161275-56953
e-mail: bushra.nazir@postgrad.manchester.ac.uk

Thank you for taking the time to read this information sheet
Appendix 18: Consent form – Health Care Professionals

Improving understanding and access to treatment for eating disorders among young British South Asian females: a qualitative study.

Consent Form

Please initial each box

1. I confirm that I have read and understood the Participant Information Sheet.

2. I understand that my participation is entirely voluntary and that I am free to withdraw at any time without my legal rights being affected.

3. I understand that if I will withdraw from the study, information collected up to the point of my withdrawal will still be used.

4. I am willing for the interview to be recorded and transcribed, also for anonymised direct quotations to be used in research presentations and publications

_________________________  ______________________  ________________________
Name of Participant         Date                      Signature

_________________________  ______________________  ________________________
Name of Researcher          Date                      Signature
Appendix 19: Thematic Maps

Thematic Map - Group 1. South Asian females with eating disorders.

- **GP** – breach of Confidentiality, family doctor, lack of understanding of ED, do not Trust, Fear of being labelled, Avoidance
- **Mental health services** – lack of understanding, long waiting lists, and avoidance of seeking help.
- **Health Problems as a result of ED** – stomach pains, rotten teeth, problems with monthly menstrual cycle, lack of energy, feeling cold.
- **Development of eating disorder** – a way of coping with pressure, having control, Body image, help seeking behaviour, a way of protesting, keeping slim, relieving stress, releasing anger, attention seeking.
- **Freedom** – Being secretive, making own choices
- **Marriage/marriageability** and commodity – staying in an unhappy marriage to please parents and community. Pressure from family and community to be a perfect package for marriage.
- **In-laws** – Controlling, obedient to, have to look after, live with, domestic duties
- **Cultural conflict/identity** – peer pressure, family pressure, keeping to traditions, parents’ fear of losing culture
- **Self-harm and suicidal tendencies** – as well as ED other forms of relieving pressure.
- **Family** – parental control, lack of understanding about ED, lack of support, expectations.

Group 1. Asian females with eating disorders.
Pressure on girls
To look their best, be a good cook, have a high level of education.

Group 2 A: Sibling

GP - Lack of support and understanding

Health Services - lack of understanding

Health Problems as a result of ED - stomach ache, loss of weight, no periods,

Food / force feeding

Home not a good environment

Clash of cultures at home

Communication at home - “No one talks about the main issues at home until things get worse”.

Overcontrolling parents - Particularly the mother

Parents - Lack of understanding support

Change in Asian woman’s role

Cultural conflict/identity - what others say

Stigma - being labelled as mentally ill

Pressure to look after the family - mostly pressure on the older sister or the sensible one, to look after the parents and siblings financially and otherwise.

Marriage/marriageability/Proposal - daughter must be a perfect package for marriage.

Family & Food - family centred around food

Media Influence

Overcontrolling parents

Parents

Cultural conflict/identity

Stigma

Pressure to look after the family

Communication at home

GP Lack of support and understanding

Health Services - lack of understanding

Health Problems as a result of ED - stomach ache, loss of weight, no periods.
Thematic Map Group 2 B. Parents – Initial codes

Group 2 B: Parents

- **GP** lack of understanding and support for the patient and the family
- **Denial of ED** - afraid, blocking the problem, lack of understanding
- **Father** Lack of support to the mother
- **Cultural conflict/identity** - feel a failure as a mother, keeping to traditions, parents’ fear of losing culture
- **Health services** - lack of understanding
- **Health Problems as a result of ED** - Parents worried about daughters starting their periods at the time of puberty. This is the stage when the alarm
- **Anger and frustration** - Parents feeling angry and frustrated with their daughter with ED.
- **Force feeding** - Mothers force feeding their daughter to make sure she eats meal
- **Community** - What will people say, fear of stigma from the community
- **Marriage/marriageability** - daughter must be a perfect package for marriage.
Health Care Professionals

Front-Line Staff
- Personal experiences of conflict with parents and dual culture
- Pressure on GPs

Client’s issues
- Fear of being seen accessing services by community & family
- Parental-conflict & pressure
- Freedom of choice

Duties
- Fear of stigma
- Lack of support from
- Media influence
- Cultural Conflict
- Resources – funding cuts

Lack of awareness and understanding among Asian parents of ED
- Asian females experience barriers in accessing
- ED measuring tools not appropriate for

Resources
- Lack of awareness among healthcare professionals of ED and South Asian females
- Referrals – long waiting lists

GP confidentiality a concern for young adults (have to be accompanied by a family member)
- Going over and above the line of duty-
- Expectations of frontline staff from organisations– Act as interpreters

Fear of stigma

Thematic Map – Group 3 Health Care professionals
Appendix 20: Tables of possible themes

**Phase three:** Searching for themes the researcher attempted to sort out the identified codes into provisional themes by transferring the codes from the thematic maps into a table giving codes titles (Please see below). This offered useful ways to think about grouping codes within specific themes, considering possible variations, defining potential main and sub-themes and considering how they might relate.

**Possible themes for ED participant.**

<table>
<thead>
<tr>
<th>Theme 1: Perceived Family/Parental and Community pressure</th>
<th>Theme 2: In-Laws, marriage and marriageability</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) Family/parental</td>
<td>(A) Marriage</td>
</tr>
<tr>
<td>(i) Lack of Support</td>
<td>(i) Forced</td>
</tr>
<tr>
<td>(ii) Force feeding</td>
<td>(ii) Unhappy</td>
</tr>
<tr>
<td>(iii) Expectations</td>
<td>(iii) Trapped</td>
</tr>
<tr>
<td>(iv) Control / No freedom</td>
<td>(iv) Stay to please</td>
</tr>
<tr>
<td>(v) Interfering</td>
<td>(C) In-Laws</td>
</tr>
<tr>
<td>(vi) Caste out of the family</td>
<td>(i) Duties</td>
</tr>
<tr>
<td>(vii) High value commodity</td>
<td>(ii) Abuse</td>
</tr>
<tr>
<td>(viii) Avoidance</td>
<td>(iii) Interfering</td>
</tr>
<tr>
<td>(ix) Denial</td>
<td>(iv) Control</td>
</tr>
<tr>
<td>(B) Community</td>
<td>(v) Having to live with them</td>
</tr>
<tr>
<td>(i) Being judged</td>
<td>(vi) Expectations</td>
</tr>
<tr>
<td>(ii) Out-casted/shamming</td>
<td>(v) Denial</td>
</tr>
<tr>
<td>(iii) Labelled</td>
<td>(E) Marriageability</td>
</tr>
<tr>
<td>(iv) A need to give a good impression</td>
<td>(F) Commodity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 4: Coping with pressure and Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) Eating less as a means of:</td>
</tr>
<tr>
<td>(i) Taking control</td>
</tr>
<tr>
<td>(ii) Protesting against pressure</td>
</tr>
<tr>
<td>(iii) Keeping slim</td>
</tr>
<tr>
<td>(iv) Relieving stress</td>
</tr>
<tr>
<td>(v) Hiding their illness</td>
</tr>
<tr>
<td>(vi) Denial</td>
</tr>
<tr>
<td>(vii) Guilt</td>
</tr>
<tr>
<td>(viii) Coping</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme 5: Access to treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) Avoidance of professional help</td>
</tr>
<tr>
<td>(i) Stigma/label</td>
</tr>
<tr>
<td>(ii) Fear</td>
</tr>
<tr>
<td>(iii) Confidentiality</td>
</tr>
<tr>
<td>(iv) Denial</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(B) Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) Lack of information</td>
</tr>
<tr>
<td>(ii) Long waiting lists</td>
</tr>
<tr>
<td>(v) Lack of support</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(C) Types of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) Counselling</td>
</tr>
<tr>
<td>(ii) Force feeding</td>
</tr>
<tr>
<td>(iii) Psychotherapy</td>
</tr>
<tr>
<td>(iv) CBT</td>
</tr>
<tr>
<td>(V) Private</td>
</tr>
</tbody>
</table>
### Theme 1: Observing changes in individual with Eating Disorder
(A) Physical Changes  
(i) Loss of weight  
(ii) Stomach pains  
(iii) Hair loss  
(iv) Joint pains  
(v) Delayed puberty / periods stop  
(B) Behavioural Changes  
(i) Not eating with the family  
(ii) Withdrawn  
(iii) Aggressive / frustrated  
(iv) Moody

### Theme 2: Sibling perception of pressure on sister with eating disorder
(A) Clash of cultures at home  
(B) Pressure to look after the family  
(i) Look after sick parent  
(ii) Contribute financially  
(C) Controlling mother  
(i) Afraid daughter may lose culture  
(ii) Control on daughters daily activities  
(D) Community  
(i) What will people say?  
(E) Body image  
(i) Media influence  
(ii) Comments from people  
(F) Change in the role of Asian women

### Theme 3: Parents perception of daughter with ED
(A) Fear of losing culture  
(i) Control on daughter  
(B) Worried about daughters fertility  
(C) Frustration/ Anger  
(i) Why starve yourself?  
(D) Force feeding  
(i) Food – making sure everyone is healthy  
(E) Lack of understanding of Eating Disorders

### Theme 4: Health service
(A) Family GP  
(i) Not identifying ED in Asian females  
(ii) Not referring to the right service  
(B) Mental Health services  
(I) Not equipped to meet the needs of Asian females with ED  
(II) Not enough referrals therefore don’t recognise ED in Asian females
### Possible theme for Health Care Professionals.

<table>
<thead>
<tr>
<th>Theme 1 Health Care Professionals</th>
<th>Theme 2 Clients issues from the perspective of the health professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A) Training needs</td>
<td>(A) Marriage</td>
</tr>
<tr>
<td>(i) Cultural competence</td>
<td>(i) Forced</td>
</tr>
<tr>
<td>(ii) Resources - cuts</td>
<td>(ii) In-laws</td>
</tr>
<tr>
<td>(B) Service provision</td>
<td>(B) Parents</td>
</tr>
<tr>
<td>(i) Managing waiting lists</td>
<td>(i) Lack of understanding ED</td>
</tr>
<tr>
<td>(ii) Pressure on GPs</td>
<td>(ii) Lack of Support</td>
</tr>
<tr>
<td>(iii) Lack of knowledge about ED</td>
<td>(iii) Conflict around freedom of choice</td>
</tr>
<tr>
<td>and Asian females</td>
<td>(iv) Wearing a head scarf</td>
</tr>
<tr>
<td>(iv) ED a hidden problem in Asian</td>
<td>(v) Pressure of duties</td>
</tr>
<tr>
<td>females</td>
<td></td>
</tr>
<tr>
<td>(v) Referral’s – not enough therefore don’t recognise ED in Asian females as an issue</td>
<td></td>
</tr>
<tr>
<td>(vi) Not identifying ED in young Asian females</td>
<td></td>
</tr>
<tr>
<td>(vii) Services not equipped to meet the needs of Asian females with ED</td>
<td></td>
</tr>
<tr>
<td>(viii) ED measuring tools not appropriate to use on Asian females</td>
<td></td>
</tr>
<tr>
<td>(C) Front line staff</td>
<td>(C) Cultural conflict</td>
</tr>
<tr>
<td>(i) Expectations of Asian front-line staff by managers and community</td>
<td></td>
</tr>
<tr>
<td>(ii) Going over and above the line of duty</td>
<td></td>
</tr>
<tr>
<td>(iii) Personal experiences</td>
<td>(i) Changing attitudes</td>
</tr>
<tr>
<td>(iv)</td>
<td>(ii) Community</td>
</tr>
<tr>
<td></td>
<td>(d) Peer pressure</td>
</tr>
<tr>
<td></td>
<td>(e) Media influence</td>
</tr>
<tr>
<td></td>
<td>(i) Bollywood</td>
</tr>
</tbody>
</table>

### Theme 3 Lack of understanding of ED

- **(A) Parents**
- **(B) Health Care professionals**
- **(C) Lack of information on Ed and South Asian females**
- **(D) ED a hidden problem**