

**Treatment Seeking for Binge Eating Disorder**

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**Thesis submitted in partial fulfilment of the requirements of  
Staffordshire and Keele Universities for the jointly awarded degree  
of Doctorate in Clinical Psychology**

**August 2016**

<b>Title of degree programme</b>	Doctorate in Clinical Psychology
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<b>Initial date of registration</b>	September 2013

### **Acknowledgements**

I would like to acknowledge Dr. Helena Priest, both as a personal tutor and research supervisor, for your support, extensive knowledge and confidence in me throughout all stages of both the Doctorate and this thesis.

I would like to acknowledge Dr. Bryony Bamford for her continued support, expertise and feedback. I would like to give you my recognition for being such an inspirational first supervisor and for not only stimulating my interest in eating disorders but also to pursue a career in Clinical Psychology.

Dr. Kierron Worley, thank you for your motivation in ensuring that recruitment was possible and for your continued support and feedback. I am grateful for your time and the many thought-provoking conversations we have had along the way.

Also to acknowledge the DClinPsy staff team and peers in my cohort; in particular to Dr. Ken McFadyen for facilitating the IPA support group; and to Jo Murray for her friendship, support and thoughtful feedback. The many conversations we have had along the way have not only had an impact on this thesis but also my clinical work. Thank you to my family; parents and grandparents for always supporting and believing in me and in particular, Michael Evans, for meticulously reading draft after draft...

I would like to thank all of the service users who provided me with feedback during the development of this research proposal and design. Most importantly, I would like to give my gratitude to each and every individual who volunteered to share with me their experiences; without your honesty and generous participation this research would not have been possible.

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### **List of Abbreviations**

AN	Anorexia Nervosa
APA	American Psychiatric Association
BED	Binge Eating Disorder
BN	Bulimia Nervosa
BPS	British Psychological Society
CASP	Critical Appraisal Skills Programme
CCAT	Crowe Critical Appraisal Tool
CBT	Cognitive Behavioural Therapy
DCP	Division of Clinical Psychology
DSM-5	Diagnostic Statistical Manual of Mental Health Disorders-Fifth Edition
ED	Eating Disorder(s)
EDE	Eating Disorder Examination
EDE-Q	Eating Disorder Examination Questionnaire
EDNOS	Eating Disorder Not Otherwise Specified
FA	Framework Analysis
GP	General Practitioner
GT	Grounded Theory
HCPs	Healthcare Professionals
IPA	Interpretative Phenomenological Analysis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
R&D	Research and Development Approval
SU	Service User
UK	United Kingdom
US	United States

### Thesis Abstract

The aim of this thesis is to explore the process of treatment seeking for eating disorders (EDs). EDs are frequently associated with psychological distress and poor quality of life, and it is widely recognised that there is a large proportion of individuals with EDs who are not accessing appropriate specialist treatment. This is concerning given that delays in treatment have been associated with poorer outcomes. A review of the literature regarding the experience of treatment seeking for an ED was carried out, this included: anorexia nervosa (AN); bulimia nervosa (BN); eating disorder not otherwise specified (EDNOS); binge eating disorder (BED); and sub-threshold eating difficulties. This review highlighted five themes across the papers; social stereotypes and norms; external factors; client (internal) factors; interpersonal factors; and gender. Critical review of eight papers found inconsistencies in the methods used for screening EDs and also large heterogeneity in the ED samples used. These methodological limitations should be taken into account when considering the findings. Paucity in research focusing specifically on treatment seeking for BED was highlighted. In response to this gap in the literature, Interpretative Phenomenological Analysis was used to explore the lived experience of people treatment seeking for BED. This analysis resulted in the following themes: *the self as a barrier; the overlooked eating disorder; factors contributing to treatment seeking and disclosure; and making sense of BED*. These findings are integral to engaging individuals with BED in services and ensuring that this often overlooked group are not left without appropriate treatment. These themes are considered in relation to existing theory; together with clinical implications and directions for future research. A reflective commentary considers personal reflections of completing the research; the influence of society on weight and shape; EDs and gender; and the controversial topic of psychiatric diagnosis.

## **Paper 1: Literature Review**

### ***“Treatment seeking as a process”***

#### **Treatment Seeking for an Eating Disorder: A Review of the Literature (2009-2015)**

Paper 1 has been written with the intention of submission for publication to the European Eating Disorders Review; author guidelines for manuscript submission can be found in Appendix A.

The write up for this paper has used size 12 Arial font and has extended left hand margins, in accordance with the University requirements for thesis submission. Supplementary material has been included for the purpose of the final thesis write up in order to aid the reader; however these additional sections will be removed from the manuscript before submission to the European Eating Disorders Review.

### Abstract

Eating disorders including anorexia nervosa (AN), bulimia nervosa (BN) and binge eating disorder (BED) are frequently associated with additional psychological difficulties and poor quality of life. It has been well documented that only a minority of individuals experiencing eating difficulties access appropriate specialist treatment interventions. The aim of the review is to critically appraise and synthesise recent literature (2009 – 2015) pertaining to the treatment seeking experience for eating disorders (EDs). Relevant search terms were developed and utilised in order to systematically search key databases until April 2016. Eight studies met the inclusion criteria and were each assessed for methodological quality and rigour. The methods used for screening EDs were found to be inconsistent and frequently heterogeneous samples were recruited. This has implications both for the generalisation of findings and for ascertaining whether there are similarities or differences across the EDs. Four themes were identified, which were grouped under the over-arching theme of '*treatment seeking as a process*'. These themes were: social stereotypes and norms; external factors; client (internal) factors; interpersonal factors; and gender. Clinical implications specifically focusing on aiding disclosure and thus facilitating treatment seeking are discussed, along with limitations and directions for future research.

*Keywords:* eating disorders; anorexia nervosa; binge eating disorder; bulimia nervosa; treatment seeking; help seeking.

### Treatment Seeking for an Eating Disorder

Eating disorders (EDs) are characterised by disturbances in eating behaviours, which are frequently accompanied by feelings of distress and concerns about body weight and/or shape. Individuals with an ED frequently judge their self-worth according to their shape and weight; such over-evaluation of shape and weight is present across all EDs (Fairburn, 2008). EDs are commonly associated with physical health complications and psychological difficulties including low self-esteem, depression, anxiety and low quality of life, making EDs some of the most complex mental health difficulties to treat (Crow et al., 2009; Fairburn & Harrison, 2003; Jenkins, Hoste, Meyer, & Blissett, 2011). Associations have been identified with increased suicide rates and EDs have the highest mortality rate when compared to other mental health difficulties (Arcelus, Mitchell, Wales, & Neilsen, 2011; Crow et al., 2009).

The classification for EDs was updated in 2013 when the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was published (American Psychiatric Association [APA], 2013). In addition to revisions being made to the existing diagnoses of anorexia nervosa (AN) and bulimia nervosa (BN) and the removal of eating disorder not otherwise specified (EDNOS), for the first time binge eating disorder (BED) was included as a distinct diagnosis.

According to DSM-5 criteria the most prominent feature of AN is extreme low body weight, which is caused and maintained by restricted eating and is accompanied by an intense fear of weight gain (APA, 2013). Individuals with AN frequently do not recognise the severity of their low weight. BN is characterised by frequent episodes of binge eating, in which a loss of control is experienced. Compensatory behaviours are adopted with the intention to prevent weight gain; these often include: self-induced vomiting; laxative misuse; or excessive exercise. BED is defined as recurrent episodes of binge eating; in addition individuals experience a loss of control; eating rapidly; and distress relating to the binges. There are no associated compensatory behaviours. The DSM-5 diagnostic criteria for AN, BN and BED are listed in Appendix B.

### **Eating Disorder Prevalence and Incidence**

Incidence rates refer to the number of new cases detected, which is usually over a specific time period. A recent study has determined the primary care incidence rates for EDs between the years 2000 and 2009 in the United Kingdom (UK) (Micali, Hagberg, Peteren, & Treasure, 2013). A significant increase was found for the incidence of diagnosed EDs between these dates for both males and females and the annual incidence of first time diagnosis significantly increased over time, between 2000 and 2009 there was a total of first time diagnoses was 9,120. It cannot be determined whether this increase is indicative of improved recognition and ED diagnosis or an increase in individuals developing an ED. Micali et al. (2013) argued that these incidence rates, which were derived from '*detected*' rates (i.e. diagnosed EDs) rather than community incidence rates, allow a true reflection of need in healthcare; however it remains unclear whether there is a true increase or indeed more sophisticated detection.

Prevalence rates refer to the number of EDs that are recorded at a single point in time. There are variations within the reported prevalence rates of EDs; this is likely to be due to the complexity of EDs causing an inconsistency in diagnoses and differences in the samples used; for example, from the community or primary care. As a result, this means that historical data is often relied upon. The b-eat ED charity has recently provided an estimation of the prevalence rate for EDs in the UK (b-eat, 2015). This estimation was made through refreshing the data from the National Collaborating Centre for Mental Health's Report (NICE, 2004) to include the latest UK population statistics, this includes BED and in particular males experiencing BED, which has historically been omitted. This led to a higher estimated prevalence rate of 724, 845 in total for all of the EDs (Table 1).

Table 1

*Estimated Prevalence of Eating Disorders in the United Kingdom (March, 2015)*

Eating Disorder Type	n (estimated)
AN	6,819
BN	360,764
BED	357,261
Total	724,845

*Note.* AN = anorexia nervosa; BN = bulimia nervosa; BED = binge eating disorder.

### Treatment Seeking<sup>1</sup>

A review of the literature on the proportion of individuals in the community with a diagnosable ED found that 67-83% did not seek appropriate specific treatment for an ED (Hart, Granillo, Jorm, & Paxton, 2011). Longer delays in accessing treatment have been associated with poorer outcomes and if EDs are detected early, then prognosis is more favourable (Reas, Williamson, Marin, & Zucker, 2000). Evidence suggests that there is an average delay of four years between symptom onset and accessing treatment, which can extend up to 10 years (Deter & Herzog, 1994; Cachelin, Rebeck, Viesel, & Steigel-Moore, 2001; de la Rie, Noordenbos, Donker, & van Furth, 2006). It is therefore essential that individuals seek and access appropriate specialist treatment in a timely manner.

Although there is empirical support for the effectiveness of psychological therapies for EDs (e.g. Hay, 2013), it is widely recognised that a large proportion of individuals with an ED do not seek timely treatment for their eating difficulties (Cachelin & Striegel-Moore, 2006; Mond, Rodgers, Hay, & Owen, 2007; Striegel-Moore et al., 2005). This low treatment uptake is particularly concerning given that AN has the highest mortality rate compared to other psychiatric disorders; this is due to elevated suicide rates in individuals with AN. In addition there are further medical complications, some of which are also seen in individuals

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<sup>1</sup> 'Help seeking' and 'treatment seeking' are often used interchangeably within the literature, therefore for consistency 'treatment seeking' will be used throughout this review.



experiencing BN and BED (Birmingham, Su, Hlynsky, Goldner, & Gao, 2005). Low disclosure rates may contribute to detection rates being reported as low as <10% (Johnson, Spitzer, & Williams, 2001).

It has been documented that when individuals with bulimic type EDs receive treatment this is frequently for a comorbid mental health difficulty; associated medical complications; or perceived weight difficulties rather than eating difficulties (Mond et al., 2007). For females within the community, beliefs and attitudes relating to binge type eating difficulties are likely to contribute to low treatment seeking rates (Mond, Hay, Rodgers, & Owen, 2008). Similar findings were reported among obese patients with a diagnosis of BED, physical health concerns were the most commonly cited reason for seeking treatment rather than specific eating concerns (Reas, Masheb, & Grilo, 2004). This lack of recognition and low mental health literacy could be a contributory factor to the low treatment uptake. Binge eating difficulties that do not involve purging behaviours are often not readily recognised as an ED by either the affected individual or by primary care practitioners (Huon, Brown, & Morris, 1988; Striegel-Moore et al., 2001). Due to the ego-syntonic nature of AN, individuals are often ambivalent towards seeking treatment (Holliday, Wall, Treasure, & Weinman, 2006). Individuals meeting the diagnostic criteria for an ED, including AN and BN, have been found to not recognise difficulties with their eating and to believe that they are not significant enough to require any treatment (Hart et al., 2011).

Hepworth and Paxton (2007) used a concept mapping approach to identify factors associated with problem recognition, treatment barriers and prompts for treatment seeking in individuals with BN and binge related difficulties. Commonly cited barriers include social anxiety (Goodwin & Fitzgibbon, 2001); individuals not believing that their eating difficulties warrant therapeutic intervention ('denial') (Meyer, 2001); stigmatisation; and shame (Hepworth & Paxton, 2007). These were distinguished as occurring at a personal level (e.g. shame and fear of stigma; believing seeing a therapist is a sign of weakness; expectations or lack of awareness of treatment) and at a system level (e.g. cost; inaccessible services; long waiting lists and practical constraints such as

transport or child care) (Cachelin & Striegel-Moore, 2006). Prompts to seeking treatment have also been identified, which included increased symptom severity; increased psychological distress; perceived lack of control and health problems (Hepworth & Paxton, 2007).

Recent figures have shown that 86% of ED inpatient services in England have experienced an increase in the number of ED patients being treated under the Mental Health Act (Sly, 2015). This could reflect individuals not accessing treatment early enough, or that due to limited resources services are responding preferentially to severe and enduring EDs. Given that many individuals do not readily seek help for an ED, it is important that treatment seeking for EDs is better understood. Further research is therefore needed to enhance understanding about the potential barriers and facilitating factors for treatment seeking for an ED, paying particular attention to individuals' experiences of treatment seeking.

### **The Impact of Culture and Context**

The impact of culture on the development of EDs has long been discussed within the literature and it is widely recognised that these difficulties with eating are more prevalent in Western culture. It has been proposed that there are cross-cultural differences regarding the importance and emphasis placed upon thinness for women, in particular cultural differences regarding the prevalence of BN have been reported (Miller & Pumariega, 2001). Western society cultivates a context which surrounds individuals with information emphasising dieting; food; fitness; and cosmetic surgery in a strive for 'perfection'; however it is noteworthy that whilst such culture may have an impact, not all individuals that are exposed to such environments develop eating difficulties (Keel & Klump, 2003). Whilst it is recognised that there are psychological reasons for the development of eating difficulties, for example, trauma, there are also proposed to be culturally induced manifestations (Hesse-Biber, Leavy, Quinn & Zoine, 2006). It is therefore important to recognise and take into account the broader social and economic contexts in which individuals live. In addition to specific psychological factors it is necessary to consider the perpetuating effect that society and culture may have on the

development of EDs, which is of particular interest when thinking about prevention through targeting specific attitudes and mind-sets (Haworth-Hoepfner, 2000).

A recent review has demonstrated the effects of social networking sites on body image and disordered eating, in particular uploading and viewing images and seeking negative feedback was seen as problematic (Holland & Tiggemann, 2016). Whilst this research is in its infancy it has been suggested that social comparison relating to physical appearance may be an important underlying process within the relationship between disordered eating and social media use.

### **Rationale for the Review**

To date, research has primarily focused on investigating the barriers and facilitators for accessing treatment. Since 2010, qualitative research designs have begun to explore in more detail individuals' experiences of the disclosure and treatment seeking process. Taking this into account, a review of the literature pertaining to the treatment seeking experience for an ED is now warranted.

A literature review was completed in 2009 as part of a Doctoral thesis, this focused on the specific factors that inhibit or facilitate treatment seeking for an ED (Gilbert, 2009). It was therefore decided for this current paper to review the literature from 2009 onwards in order to provide a contemporary picture. Since 2009 there has been a sizable amount of research that has continued to focus on the barriers and facilitators and the process of treatment seeking (a scoping search revealed 183 papers published between 2009 and 2015).

This review focuses on adults (i.e. individuals over the age of 18 years). The rationale for this was due to clinical guidelines globally recommending different treatment approaches for EDs in children and adolescents compared to adults (NICE, 2004; APA, 2006). Within a child and adolescent population, family based therapy is the recommended first line of intervention; however for adults individual psychological therapy is advocated.

### **Review Question**

What is known about the experience of adults seeking treatment for an ED?

### **Aim**

This review aims to provide an overview of the contemporary empirical literature concerned with the experience of treatment seeking for an ED. The selected studies are described and their methodology critically appraised; a synthesis of the pertinent themes is then presented. This synthesis and critical appraisal are then used to provide recommendations for future research and to inform clinical practice.

## **Methodology**

### **Preliminary Search**

The Cochrane Library was searched to determine whether there were pre-existing review articles. The search terms “anorexia nervosa” OR “bulimia nervosa” OR “binge eating disorder” OR “eating disorders” AND “help seeking” OR “treatment seeking” were used. This identified systematic review papers concerning treatment outcomes, medication and psychological therapies for ED, but none focused on treatment seeking.

This search was repeated using EBSCOhost, which generated 12 results, one of which was relating to treatment seeking. This article reviewed the literature regarding treatment seeking among community ED cases (Hart et al., 2011). It was concluded that the experiences of treatment seeking for ED had not been reviewed and that this paper would make an original and important contribution to the field.

### **Development of Search Terms**

A scoping search using Google Scholar and key peer-reviewed journals (International Journal of Eating Disorders and the European Eating Disorders Review) generated an overview of the key words used in existing research. To ensure that the search terms to be used were comprehensive, the thesaurus tool and Medical Subheading vocabulary were used. Following discussions with a clinical psychologist and ED research fellow, the final search terms were developed (Figure 1).

("binge eat\*" OR "compulsive eat\*" OR binge-eat\* OR overeat\* OR "emotional overeat\*" OR "comfort eat\*" OR "DSM 5 binge\*" OR bulimi\* OR "bulimia nervosa" OR anorexi\* OR "anorexia nervosa" OR ednos OR "eating disorder not otherwise specified" OR "eating disorder\*" OR "disordered eating")  
 AND  
 ("help seek\*" OR help seek\* OR "treatment seek\*" OR treatment-seek\* OR access service OR treatment barrier OR barrier\* OR "access he\*" OR "access treat\*" OR "health care seek\*" OR "support seek\*" OR "intervention seek" OR "treatment facilitat\*")  
 AND  
 (experience\* OR perspective\* OR view OR perception\* OR attitude\*)

*Figure 1. Final search terms for the systematic search.*

## **Inclusion and Exclusion Criteria**

### **Inclusion**

- Studies which included participants over the age of 18 years
- Published in the English language
- AN, BN, BED or EDNOS or sub-threshold eating difficulties
- Focus on barriers/facilitating factors to accessing treatment and/or the experience of accessing specialist treatment
- Published in a peer-reviewed journal.

### **Exclusion**

- Studies with a specific focus on:
  - Participants classified as 'obese'
  - Weight loss
  - Surgical interventions (e.g. bariatric surgery).

## **Search Strategy**

The search terms were entered into EBSCOhost database on 8<sup>th</sup> October 2015 and generated 648 results. Following limiters being set (English language; over 18 years) and duplicates being removed, 298 results remained. The same search terms were entered into Web of Knowledge, via the Web of Science Database Host, which produced 565 results. The results from the two searches were combined and duplicates were removed using the RefWorks programme; from which 653 results remained. These were then screened using a three stage screening process, which consisted of screening by title, abstract or full text.

To ensure that no key papers were omitted, a manual search was carried out using Google Scholar and using a key word search within peer-reviewed ED journals. The reference lists of articles selected for full

text screening were also examined, which generated four additional results. A weekly alert was set up to identify newly added results from the EBSCOhost database ascribed to the entered search strategy. This was active October 2015 – March 2016 and did not generate any new relevant results.

### **Screening Process**

A clinical researcher independently carried out the title screening process to ensure inter-rater reliability, from which an 88% agreement was achieved. The title screening process involved retaining papers for further screening or rejecting the papers, based on the title. Any discrepancies were discussed within supervision and a mutual agreement was made regarding the papers under question. Following the title screening, 84 articles remained for screening by abstract and each were considered against the inclusion and exclusion criteria, which left 34 articles for full text screening.

To ensure that the literature search was comprehensive, an additional scoping search was carried out using ProQuest and the British Library EThOS Database, which revealed the aforementioned thesis reviewing the barriers and facilitating factors for treatment of ED (Gilbert, 2009). Due to an inclusion criterion being 'peer reviewed articles' this was not included within this review. As a result of this thesis being found, the date limiter of 2009-2015 was applied, which led to 13 articles being excluded. This left 34 full text articles for in-depth review. The search strategy is detailed in Figure 2.

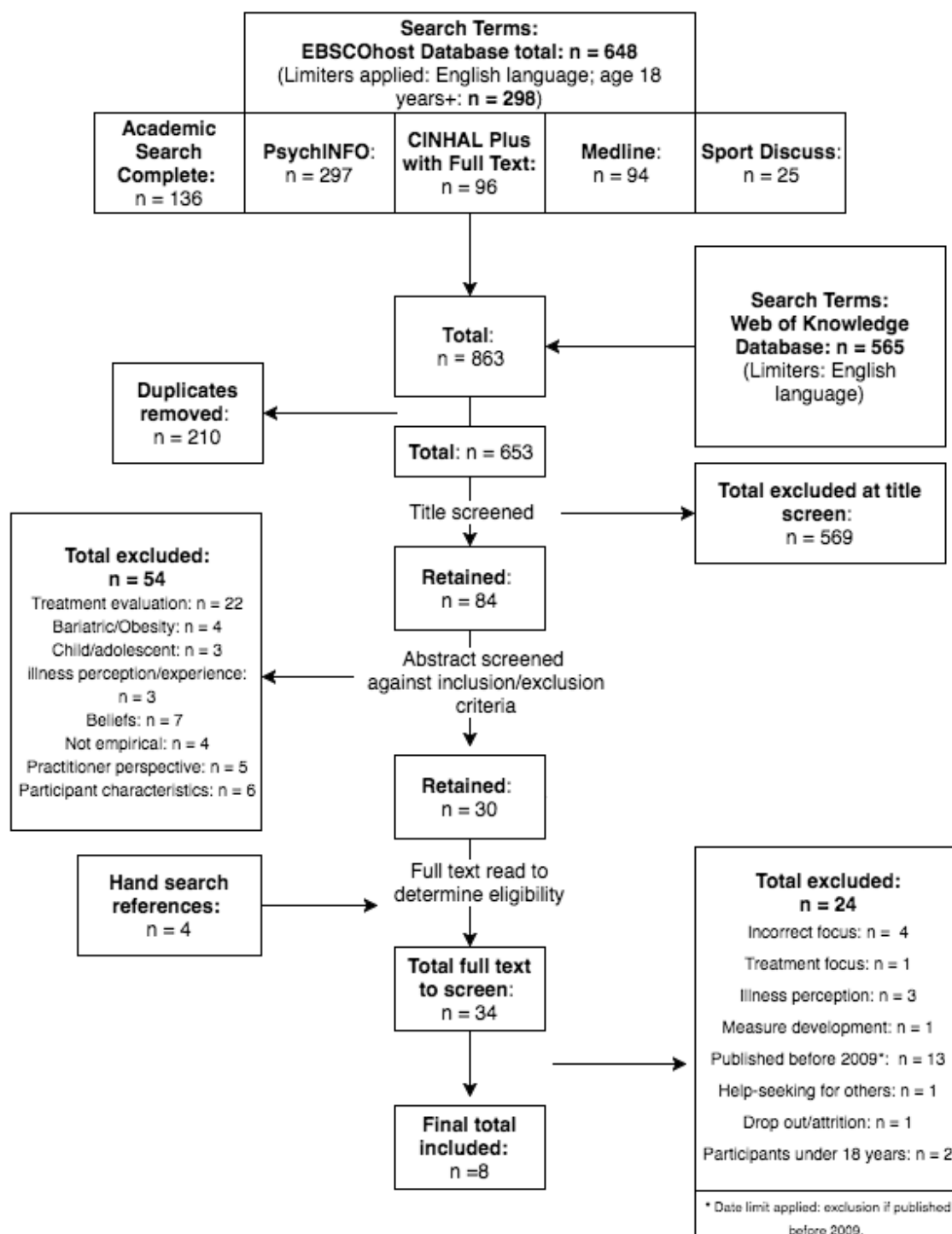


Figure 2. A flow chart of the systematic review process.

## **Quality Assessment**

Following screening, eight full texts were left for critical review: six qualitative and two quantitative. 'Quality' refers to the degree to which a study employs measures in order to minimise bias and error in its design, conduct and analysis (Khan, Kunz, Kleijnen, & Antes, 2003). Although the methodological criteria used varies according to research design there are fundamental principles that underpin the critical appraisal process (Young & Solomon, 2009). The Critical Appraisal Skills Programme (CASP; 2013) was used for the qualitative studies and the Crowe Critical Appraisal Tool (CCAT) (2013) checklist was used for quantitative studies (Appendix C).

### **CASP**

The CASP has 10 questions, which places emphasis on the rigour, credibility and relevance of the study (CASP, 2013). Each question is scored (0 - 2), which allows a total credibility score to be calculated. It has been recommended that particular attention should be given to the data collection and methodological approach adopted (Dixon-Woods, Shaw, Agarwal, & Smith, 2004). The calculated quality scores for each qualitative paper can be found in Appendix D.

### **CCAT**

This checklist was selected due to its good construct validity and inter-rater reliability; there are eight different domains considered, each of which is given a score out of 5 (Crowe & Sheppard, 2011). The total score across the eight categories is then calculated, with the highest possible score being 40. A higher score represents higher quality; the domain and total scores for the quantitative studies can be found in Appendix E. The Downs & Black Checklist (1998) was not utilised due to its focus on intervention, which was not perceived to be relevant for the studies selected for this review.

The detailed assessment of quality across different research designs aims to facilitate the synthesis and interpretation of heterogeneous results (Kmet, Lee, & Cook, 2004). Inter-rater agreement with a clinical supervisor yielded 84% agreeability. A categorical method was used to assess the quality of the papers in relation to the other



papers critically appraised in this review (Appendix D; Appendix E) this is due to inconsistencies being reported when numerical ranking is utilised (Greenland & O'Rourke, 2001).

## **Results**

### **Study Characteristics**

An overview of the articles' key findings, sample demographics, data analysis and the strengths and limitations can be found in Table 2. Many of the studies included samples consisting of heterogeneous ED types. It is noteworthy that diagnosis is considered to be a positivist concept; this concept suggests that there is a direct relationship between the world and individual's understanding of it. Positivists therefore believe that it is possible to describe an object or a phenomenon and to be able to get this 'right' (Willig, 2013). Qualitative research methods however do not adopt this epistemological position and are more concerned with meaning making; for example, how individuals make sense of the world. It is acknowledged that the researcher is implicated within this process and that there is not one 'right' interpretation of a phenomenon; such epistemological positions include critical realism and social constructionism (Willig, 2013). Whilst qualitative studies frequently recruit based on diagnostic categories, for this review it is the phenomena of treatment seeking rather than experiences relating to diagnosis that the studies are concerned with.

Due to the greater number of qualitative designs in this review a qualitative synthesis was used to discuss the main emergent themes (Boland, Cherry, & Dickinson, 2014). The review is divided into qualitative and quantitative studies due to the differences in the criteria for the critical appraisal of quality. They will be discussed paper by paper in chronological order; this is in order to orientate the reader to trends in research over time, to give a clear summary of the individual papers and their relative strengths and weaknesses.

Table 2.

*Overview of Studies Investigating the Treatment Seeking Experience for an Eating Disorder*

	Sample Characteristics	ED Screening Tool	Type of Study	Study Aim	Main Findings	Strengths	Limitations
Becker et al. (2010). US	32 male and female participants.  Past or current 'concerns, symptoms or problems' regarding eating or weight.  US.	Past and prospective consumers of ED treatment.	Qualitative – qualitative methodology type not specified.	To identify and describe health consumer perspectives on social barriers to care for EDs in an ethnically diverse sample.	Most respondents (78%) endorsed at least one social barrier to care for eating or weight concerns. Perceived stigma or shame and social stereotyping had adverse impact on care. Themes: 1. Perceived social barriers to care 2. Culturally based barriers to care 3. Societal barriers: availability and affordability.	Qualitative research – scant in ED literature. Complements statistical data in elucidating the context of behaviour within personal narratives. Clinical diversity of the study sample may allow a broad perspective. Clinical implications: stigma in clinicians and laypersons, educate about the impact of low mental health literacy.	Small sample. All had attended educational programme for ED on university campus: not representative of US population Few male respondents. All had health insurance. Retrospective data – recall bias. Recruited 'eating or weight concerns' may not specifically be ED. No specificity.
Evans et al. (2011). Australia.	57 female participants only.  Current diagnosable ED.  Australia.	EDE clinical interview. Current ED. Bulimic-type ED (EDNOS = 30; BED = 8; BN = 7)	Qualitative – "Framework approach" Prospective.	Explore factors that contributed to an experience regarded as helpful or unhelpful, types of professionals from whom help was sought and potential barriers to accessing treatment identified.	Women sought help for concerns regarding perceived over-weight rather than eating, but would have welcomed questions regarding eating from professionals. Barriers = low motivation, fear of stigma and cost. Would like empathy, hope and information from professionals. 1. Factors contributing to positive or negative experience 2. Specific barriers	BN, BED and EDNOS – young adults (18-30). Aware of eating difficulties and had a diagnosis. Clinical implications and future research directions were discussed.	Heterogeneous mix of ED (BN 12%; BED 14%; EDNOS 53%; sub-threshold 21%) All female. Most frequent 'help' received was weight loss medication. Prompts received for accessing treatment and local information given.

	Sample Characteristics	ED Screening Tool	Type of Study	Study Aim	Main Findings	Strengths	Limitations
Gilbert et al. (2012). U.K.	71 female participants only.  Current diagnosis of an ED.  U.K.	EDE Q Current diagnosis. (37 binged; 23 self-induced vomiting; 14 laxative use; 27 excessive exercise.	Cross sectional. Quantitative – non parametric.	To retrospectively explore the first disclosure of eating problems and the impact of disclosure factors in subsequent treatment seeking amongst woman with EDs.	Faster access to specialist services was associated with being older at disclosure and with disclosure involving general practitioner, or individual's partner or mother. The more positively 'other initiated' disclosure was appraised, the quicker subsequent help seeking was.	Use of a valid, reliable screening tool for ED assessment. Clinical implications and future research discussed: clinicians to prompt disclosure of ED. Positive appraisal linked to faster subsequent treatment seeking but it is not possible from this study to identify the specific factors associated with positive appraisal.	No power calculation was reported. Heterogeneous ED sample recruited, unable to therefore group these for statistical analysis.
Griffiths et al. (2015). UK/US/Australia	Male and female participants.  Currently diagnosed or 'recovered' from an ED or believe self to be suffering from ED.  Australia, U.K, US.	EDE-Q	Cross sectional. Quantitative - Uni-variate ANOVA Logistic regression.	To examine sex differences in the association between stigma of seeking psychological help and the likelihood of having an undiagnosed ED.	There was an increased probability of having an undiagnosed ED for males, greater self-stigma of seeking psychological help and binge eating. An interaction between sex and self-stigma of seeking treatment was found (stronger for males).	The treatment being accessed was defined: psychological help. Large number recruited across different sites. Males – under researched area. Valid and reliable outcome measures were used and Cronbach alpha levels reported. Detail regarding recruitment and attrition. Clinical implications for addressing male stigma and early intervention.	Small number of male respondents. Subgroups of ED missed. Cross sectional design. The experience of treatment could reduce stigma. No power calculation was reported. ED was not assessed using interview method; self report only. Heterogeneous ED population.

	Sample Characteristics	ED Screening Tool	Type of Study	Study Aim	Main Findings	Strengths	Limitations
Gulliksen et al. (2015). Norway.	34 female participants only.  Diagnosis of AN.  Norway.	Self-reported: diagnosis within last 2 years. AN (DSM-IV)	Qualitative – Grounded Theory.	To explore the circumstances, reflections and reactions to first treatment contact in women with AN diagnosis using GT methodology.	Health care professionals need to demonstrate effective communication skills and have knowledge of EDs early on. Treatment goals should be explored. The main constructs identified: 1. Circumstances (initiative to conversation) 2. Reflections (challenges to treatment alliance; motives) 3. Reactions (loss of autonomy; communication; ED knowledge)	Qualitative methodology used to explore novel area. Relationship between researcher and treatment centres was discussed. Extracts provided to support the proposed constructs from a variety of participants.	No standardised measures used. Chronic AN only recruited; there was definition of 'chronic AN' provided. No theory or model was developed as a result of GT, therefore questionable if this was the most appropriate methodology.
Herman et al (2014). US	25 male and female participants.  DSM-5 criteria for BED - diagnosed or undiagnosed.  USA.	BED DSM-5 diagnosis or undiagnosed) using validated screening tool (not specified)	Focus group Coding of qualitative data	Examination of demographic and clinical characteristics and perceptions of diagnosis and treatment in participants with BED.	In the diagnosed group 54% became aware of BED through their healthcare provider (HCP). Perceived HCP focused more on physical health, judgemental about weight and did not distinguish BED and obesity. Themes: 1. Awareness/diagnoses 2. Interactions with HCPs and unmet need 3. Issues pertaining to treatment.	Inclusion of diagnosed and undiagnosed participants meeting BED criteria. Use of qualitative research methods. Semi-structured interviews.	Coding dictionary developed before data collection was completed. Participants received \$250 for participation. Invalidated screening measure used for BED – details not given. Relationship between participants and researcher not discussed.
Reyes-Rodriguez et al. (2013). US.	10 female, Latino participants.	Current or previous diagnosis BN	Qualitative – GT methodology.	Explore more fully the facilitators and barriers that may	Lack of information about EDs and lack of bilingual treatment – practical barriers. Emotional	Appropriate use of GT as lack of research within the field.	Low number of participants.

	Sample Characteristics	ED Screening Tool	Type of Study	Study Aim	Main Findings	Strengths	Limitations
	Current or previous diagnosis of BN, BED or binge eating behaviour.  US.	(3), BED and binge eating behaviour.		contribute to the engagement and retention of Latinos in ED treatment.	factors: fear of not being understood, stigma, family privacy and not being ready to change. Facilitating factors included; perception of ED severity and emotional distress. Themes: 1. Immigration stress 2. Treatment experience 3. Facilitators 4. Barriers 5. Treatment needs 6. Facilitators of treatment retention.	Development of a culturally sensitive model for ED and Latina women. Clinical implications discussed.	Did not specify whether data saturation was reached; lack of transparency in the analysis description. Heterogeneous sample: 2 participants in treatment, 2 referred for treatment and 1 recovered; diverse in stages of treatment or recovery. Healthcare professionals recruited did not work specifically in ED services – broad.
Schoen et al. (2012). US.	14 female participants only.  Past or current ED diagnosis.  US.	Self-reported: Past or current ED. AN/BN/EDNOS	Qualitative – GT	To develop a preliminary model of the help seeking process.	Gradual shift from denial to increased awareness of self and impact of illness. Impacted by interpersonal feedback, critical incidents, attitude to treatment seeking and prior treatment experiences. Components: 1. Denial and Awareness 2. Feedback 3. Critical incidents 4. Emotions 5. Attitudes towards help seeking.	Detailed description of data collection and analysis – transparent. Theoretical sampling. Defined treatment seeking as seeking 'psychological help' Sample questions from the interviews included. Preliminary model presented about the treatment seeking process.	Split of AN/BN/EDNOS not identified. Unclear how the interview schedule was developed. Heterogeneous sample of EDs and recovery status. Current and past ED symptoms (did not specify time length of previous ED) 1/3 interviewed for follow-up.

*Note.* AN – anorexia nervosa; BED = binge eating disorder; BN = bulimia nervosa; DSM-5 = diagnostic and statistical manual of mental disorders fifth edition; ED = eating disorder; EDE = eating disorder examination; EDE-Q = eating disorder examination questionnaire; EDNOS = eating disorder not otherwise specified; GT = grounded theory.

### **Qualitative Studies**

Becker, Arrindell, Perloe, Fay, and Striegel-Moore (2010) clearly defined the objective of their study, which was to identify and describe how social factors may influence access to appropriate care for EDs within an ethnically diverse population. This was an exploratory, secondary analysis using a thematic informed analysis of qualitative data, which was collected from participants who had current or past symptoms regarding eating and weight. Seventy-eight percent of respondents endorsed at least one social barrier to accessing treatment for an ED, which included the availability and affordability of healthcare. Cultural barriers were reported as perceived stigma and shame; social stereotypes; social norms and socio-demographic distance. The extracts used to demonstrate these themes were from a range of participants and the detail regarding the data analysis was a key strength. Two independent team members conducted the analysis and discrepancies were resolved through discussion with other team members, which added to the analysis credibility. This study was carried out in the United States (US) where healthcare insurance is utilised; this may limit the generalisation of findings to different healthcare systems such as the National Health Service (NHS). All respondents had health insurance, which indicates that the sample may not be representative of the US; as in 2014 10% of the US population were uninsured (Smith & Medalia, 2015). The study relied upon self-reported eating or weight concerns; therefore it is likely to relate to a broad range of concerns and severity. This study highlights the potential social barriers for eating related concerns, specifically linking ethnicity and stigmatisation to underutilisation of care.

Evans et al. (2011) explored the experiences of treatment seeking in a community sample of women with a 'bulimic type' ED, in Australia using an epidemiological study. Through framework analysis, they specifically explored which factors pertaining to the

experience of treatment seeking were helpful and which were barriers. Fifty-seven women met inclusion criteria and consented to take part; however it was not clear what these criteria were. All participants received a prompt to seek treatment and information regarding local services. It was reported that the following factors contributed to the experience: empathy and rapport; lack of judgement; stigma; not being taken seriously; and not being asked about eating. Specific barriers were: service entry criteria; lack of clinician's time; shame; and low motivation. A strength of this study was the use of the Eating Disorder Examination (EDE: Fairburn & Cooper, 1993), which is a structured interview based assessment and the Eating Disorder Examination Questionnaire (EDE-Q: Fairburn & Belgin, 1994) as part of the screening process. Both are widely reliable and validated measures for EDs (Berg, Peterson, Frazier, & Crow, 2013). In line with FA, the data were analysed and coded based on the anticipated themes, which were developed before data collection (Richie & Spencer, 1994). This deductive approach allows both a priori and emergent concepts to be explored, which is useful when addressing specific issues. The need for interventions that address these specific barriers and the benefits of professionals asking specifically about eating, particularly when individuals initially present with other concerns was discussed.

In comparison to other studies, Schoen et al. (2012) did not provide as much detail regarding their study aims, and due to the lack of existing research their aims were exploratory. They explored the processes women go through in seeking psychological treatment for an ED using grounded theory (n = 13). The inclusion criteria were intentionally broad to allow for rich description of phenomena, which included: past diagnosis of an ED by a mental health practitioner; past or current ED symptoms; and being enrolled in a US University. No exclusion criteria were given. Participants were self-selected through advertisements and ED diagnoses were self-reported by participants;



it was not clear whether any validated screening measures were administered. Schoen et al. developed a preliminary model of the treatment seeking process for ED; the main process that emerged was one of individuals transitioning from denial to awareness and consequently taking an active role in seeking treatment. Contributing to this increase or decrease in awareness was often interpersonal feedback and critical incidents. In addition, themes of treatment perceptions, emotions and attitudes to treatment seeking were reported. A key strength was the inclusion of examples of the questions asked by researchers in the semi-structured interviews. The method and analysis was described in detail and the reader was able to clearly follow the stages of analysis from coding to data saturation. Credibility of the data was ensured when there were disagreements during analysis and importantly participants were followed up and asked to provide feedback on the emerging themes, which strengthened the transparency and coherence (Yardley, 2000). The paper did not consider researcher reflexivity nor provide any data extracts to support the themes presented. Clinical implications were discussed, in particular, clinicians acknowledging the ambivalence to treatment that individuals may show and addressing barriers, such as lack of motivation.

Reyes-Rodriguez et al. (2013) stated their main objective clearly, which was to explore the facilitators and barriers that may contribute to or prevent engagement among Latinas in ED treatment, using grounded theory methodology. The study was carried out in the US and data were collected from Latina women with a history of an ED ( $n = 5$ ) and five Latino mental health providers. A telephone screen was used to explore ED symptomology and inclusion criteria; however details about how this was carried out were not included. A key strength was the detailed description of the data analysis, which demonstrated transparency. Data saturation was not discussed, which raises questions regarding the quality and richness of the data and

therefore the findings reported. Reyes-Rodriguez et al. identified six themes: immigration stress; treatment experience in the US; facilitators; barriers; treatment needs; and facilitators of retention. The authors listed detailed and appropriate data extracts and included an additional table of excerpts from the interviews, which were presented in both English and Spanish. In line with grounded theory methodology, a culturally sensitive model for Latinas with EDs in the US was presented, this considered four levels of intervention: system; providers, family; and patients.

The aims listed by Herman et al. (2014) lacked in specific detail; they included broad areas of information that were to be collected from participants with BED (diagnosed and undiagnosed). These included: participant characteristics; diagnostic pathways; treatment barriers; and preferences. Inclusion criteria included being able to speak, read and understand English, 18 years or older, willing to attend a focus group and to give informed consent; no exclusion criteria were given. A thematic informed analysis was conducted and three themes were derived, which were awareness/diagnosis; interactions with healthcare professionals (HCPs) and unmet needs; and issues pertaining to treatment. The coding dictionary was based on the semi-structured interview guide and was developed before data collection. The specific qualitative analysis used was not specified, therefore it was not possible to ascertain whether this was in line with the chosen methodology. There were a reasonable amount of data extracts given throughout the results, however the participant identification number was not given so it could not be ascertained whether a variety of participants were included, or whether they were from the diagnosed or undiagnosed group. Little difference between those with and without a formal BED diagnosis was reported regarding individual's awareness of BED and perceptions of interactions with HCPs. A number of participants reported that they became aware of their BED independently and that their initial healthcare contact was prompted

for other health needs. Shame of symptoms, practitioners' lack of time, and association with controllable over eating were commonly cited as barriers to treatment. The study findings were not clearly linked to the initial aims and there were no directions for future research offered.

Gulliksen, Nordbø, Espeset, Skårderud and Holte (2015) used grounded theory to explore first contacts with health care services in individuals who had been treated for AN. Participants with a diagnosis of AN were recruited from a specialist service in Norway. The authors did not provide detail of their specific inclusion and exclusion criteria, which may have implications for the research reliability. Participants' descriptions of the treatment seeking process, circumstances and reactions were divided into six themes: initiative to conversation; challenges to treatment alliance; treatment-seeking motive; loss of autonomy; communication skills and knowledge of ED. These were clearly displayed in a table and the complexities of the processes that play out within an initial consultation were clearly discussed. A key strength was the detail regarding the data collection and analysis, as this allowed the reader to understand and follow the procedure, including reaching data saturation. Precautions were made to strengthen the credibility of the findings and it was noted that the authors did not have any relationship to the treatment centres. The chosen methodology of grounded theory however did not appear to fit with the original aim to *explore* individuals' reactions and reflections to first treatment contact. There was no theory developed and presented, which questions the appropriateness of this qualitative method. The study findings were linked to their original aims and the challenges to clinicians and clinical implications were discussed.

## **Quantitative Studies**

Gilbert et al. (2012) focused on the initial disclosure and subsequent treatment seeking as an extension of previous research. They clearly specified their research aims, which explored the impact of: specific disclosure factors; who the individual confided in and whether 'volunteered' or 'other-initiated' disclosures influenced the time to access treatment. Individuals were recruited from a specialist ED Service in the UK ( $n = 71$ ); however the service type (inpatient; outpatient) was not disclosed, which could limit generalisability. Whilst the specific types of ED included were not reported, symptomatology was measured using the EDE-Q (Fairburn & Beglin, 1994). The use of a structured interview (Disclosure Evaluation Questionnaire [DEQ]) was described; however, it was not clear who conducted this or their involvement with the service. The DEQ measure was adapted from the Session Evaluation Questionnaire; Cronbach's alpha was used to measure internal consistency and was reported at 0.7 (Stiles Gordon, & Lani, 2002). The inclusion and exclusion criteria were not discussed. Due to the data not being normally distributed, non-parametric statistical tests were appropriately used; however a power calculation was not reported. A significant association was found between being older at first disclosure and faster access to specialist services. First disclosures to mothers and friends were significantly more common than disclosures to General Practitioners (GPs) ( $p = .01$ ). When disclosures to GPs were positively appraised this was associated with faster access to treatment ( $p = .01$ ). The authors concluded that barriers to services were likely to be a combination of patient, clinician and service based factors. They suggested that the association between being older at first disclosure and faster treatment access could reflect individuals presenting with greater distress; a timely response to severe ED presentations; or reflect the current lack of child and adolescent specialist services within the UK. Clinical implications included the need for clinicians to prompt initial disclosure and the need for specific training for primary care clinicians.

Griffiths et al. (2015) used regression to examine gender differences in the association between the self-stigma of seeking psychological help and the likelihood of having an undiagnosed ED. They hypothesised that males would be over-represented in having an undiagnosed ED and that self-stigma would predict an increase in the probability of having an undiagnosed ED, which would be stronger for males. An Internet survey was disseminated by specialist services, details of attrition rates were provided and participants were recruited predominantly across three countries (US, UK, Australia); however there were 23 'other' countries that were not disclosed ( $n = 113$ ), which could impact generalisability of the findings. Participants either had a current ED diagnosis; believed they were suffering from an ED; or were '*recovered*'. '*Recovery*' was not conceptualised and this could be a limitation as arguably it is a subjective concept. No significant differences in ED symptoms were found between the diagnosed and undiagnosed groups. Variables associated with an increased probability of having an undiagnosed ED included being male; greater self-stigma of seeking psychological help; and binge eating. The self-stigma of seeking psychological treatment and being male were independently associated with an increased probability of having an undiagnosed ED; the association between self-stigma and being undiagnosed was greater for males ( $R^2 = .49$ ,  $X^2 = 194.46$ ,  $p < .001$ ). There were male and female participants in both the diagnosed and undiagnosed groups, and whilst it is worth noting the low number of males (4.4% and 16% respectively), when using a logistic regression the assumption of normal distribution is not required. The detail of the methodology and data analyses was a particular strength and parametric and non-parametric tests were used according to data type (continuous and nominal) to investigate differences. It was not clear whether the researchers were blinded to the groups of diagnosed and undiagnosed participants, which may have implications for the interpretation of the outcome measures. Given the high levels of

undiagnosed ED, it was suggested that addressing beliefs about receiving psychological treatment for ED, particularly amongst males, is important for early intervention.

### **Methodological Considerations**

Despite the papers being methodologically sound, the following factors should be taken into account before drawing conclusions. Six of the studies included female participants only (Evans et al., 2011; Gilbert et al., 2012; Gulliksen et al., 2015; Reyes-Rodriguez et al., 2013; Schoen et al., 2012); and three studies included both male and female participants (Becker et al., 2010; Griffiths et al., 2015; Herman et al., 2013). For all studies including both sexes the percentage of females was higher (range = 60% – 95.6%) and the majority of the samples recruited were heterogeneous in terms of the presenting ED (Table 3). These gender biases and heterogeneous ED samples may have implications when generalising the findings to the male population and across different EDs.

Table 3

#### *Eating Disorders in the Reviewed Studies*

Eating Disorder Diagnosis	Number of Studies
AN	1
'ED' (AN, BN, EDNOS, BED)	6
BED	1

*Note.* AN = anorexia nervosa; BN = bulimia nervosa; ED = eating disorder; EDNOS = eating disorder not otherwise specified; BED = binge eating disorder.

Three qualitative papers (Becker et al., 2011; Evans et al., 2011; Herman et al., 2014) analysed the data based on anticipated themes or using coding dictionaries that were developed before or during the data collection. Although this was accurate and in line with the methodologies used (framework analysis; Richie & Spencer, 1994; Template Analysis; King, 1998) it can cause some potential limitations

due to the research team's ideas and experiences influencing the research. This deductive approach allows both a priori and emergent concepts to be explored; however given the paucity of research an approach with an inductive and exploratory focus might have been useful.

The relationship between the researcher and the participants was not considered or discussed in detail in any of the qualitative papers. Whilst Gulliksen et al. (2015) made reference to the researchers' relationship with the service, the implications of this were not extended. There was insufficient information regarding the reflexivity and the audit trails for the qualitative papers to determine the data collection and analysis steps, therefore it was difficult to ascertain the quality of these papers and in particular when considering the analysis coherence and transparency (Yardley, 2000). Reflexivity is frequently omitted from the discussion in qualitative research; it has been noted that the interpretative role of the researcher should be acknowledged in order to increase quality and to allow the analysis to be traced (Brocki & Wearden, 2006).

Sample sizes ranged from 71 – 475 for the quantitative studies, but none of the papers provided details regarding their rationale for the sample size used and whether this was done using a power calculation or based on previous research. Recruitment for the two quantitative studies was completed from within specialist ED services; however none provided detail about the specific service type (e.g. inpatient, day clinics, outpatient) nor the split of the sample across these different settings was not reported. This lack of detail could cause difficulties for generalising the findings.

Additionally, the context in which participants were in to complete self-report measures was not clear for all studies. This is important to consider when interpreting the findings as participants may respond in a socially desirable manner regarding their symptoms

or experiences, for example, if the researcher and/or a therapist was present during completion.

### **Main Findings**

Despite different methodological approaches to researching the treatment seeking experiences for an ED there were common themes found across the eight articles. A thematic analysis was conducted, which developed the following themes: social stereotypes and norms; external factors; client (internal) factors; interpersonal factors; and gender.

The overarching theme of '*treatment seeking as a process*' was identified as a result of these five themes. This is because different time points within an individual's journey of seeking treatment were identified. These time points could be conceptualised as an individual experiencing the onset of eating difficulties; becoming aware of difficulties; perceiving difficulties as problematic; disclosure; disclosure to GP; referral to specialist service; and finally engagement with specialist services.

**Stereotypes and norms.** Stigma was a theme across the majority of the studies reviewed; this was relating to both individual shame and self-stigma and also anticipated stigma from others, which included HCPs (Griffiths et al., 2015; Herman et al., 2014; Schoen et al., 2012). This was particularly experienced by individuals with binge tendencies, which appeared to evoke strong feelings of shame (Evans et al., 2011; Herman et al., 2014). HCP's responses to individuals was commonly cited as a barrier, particularly for individuals who were presenting with BED or for males with ED symptoms; these individuals were often misdiagnosed or their physical health symptoms/weight loss was the first priority of treatment (Evans et al., 2011; Herman et al., 2014;). When individuals perceived a lack of ED specific knowledge and awareness in HCPs, this also acted as a further barrier to seeking treatment (Evans et al., 2011; Gulliksen et al., 2015). Such stigma was also often related specifically to cultural attitudes towards



mental health and social stereotypes and norms. In addition, there appeared to be low mental health literacy particularly within ethnic minorities (Becker et al., 2010; Reye-Rodriguez et al., 2013).

It has been well documented that when compared to white women, ethnically diverse women are less likely to receive care for an ED (Cachelin, Rebeck, Viesel & Stiegel-Moore, 2001). Due to concerns regarding ethnic disparities in service access, two of the studies explored the treatment seeking journey within ethnically diverse populations. Individuals described difficulties regarding the stigma associated with having an ED, this included being identified as 'flawed' or 'weak'; being a disappointment to their families and fear of not feeling understood by family or HCPs. There was a central narrative relating to individuals hypothesising that their eating symptoms would be dismissed by HCPs and often that the relationship between ethnicity and eating difficulties was not acknowledged or explored further (Becker et al., 2010; Reyes-Rodriguez et al., 2013). This combination of society's narrative regarding EDs stereotypes and clinician's lay prior expectations may therefore mean that racial stereotypes impact on the recognition and therefore treatment of an ED.

**External factors.** There were common aspects relating to external facilitating factors: these are defined as factors that were not intrinsic to the individual. These included critical incidents; external motivation; and previous positive treatment seeking experiences (Becker et al., 2011; Evans et al., 2011; Herman et al., 2014; Reyes-Rodriguez et al., 2013; Schoen et al., 2012).

Critical incidents were reported by both female and male participants as being an important contributory factor to them seeking and consequently receiving treatment; for women these critical incidents evoked a feeling from what was described as state of denial to awareness of their difficulties (Gulliksen et al., 2015; Schoen et al., 2012). Such critical incidents included: increased severity; cost of the

ED to daily living; and feedback from others (Reyes-Rodriguez et al., 2013).

'External motivation' for treatment was commonly cited (Gilbert et al., 2012; Gulliksen et al., 2015; Reye-Rodriguez et al., 2013). The impact of family and friends was a common theme across the studies, this included encouragement and support in seeking help; the initiation by others in both acknowledging eating difficulties and consequently disclosing this to HCPs; and interpersonal verbal feedback which could be positive or negative relating to changes in weight and appearance. The impact of others contributed to the increased awareness of an ED (this will be considered within the theme of 'client (internal) factors but was the manifestation of an external factor). Consequently this led to individuals feeling supported in beginning their journey into seeking treatment; perceived lack of family support was found to be a barrier to seeking help, this was found in particular within participants from ethnically diverse backgrounds and emphasis of collectivism within the cultures (Becker et al., 2010; Reye-Rodriguez et al., 2013).

Finally, an additional external factor commonly cited in studies that were conducted within the US was cost as a perceived barrier to accessing appropriate treatment. This was due to individuals not having sufficient healthcare insurance in order to access appropriate and specialist treatment (Becker et al., 2010; Herman et al., 2014; Reye-Rodriguez et al., 2013).

**Client (internal) factors.** Factors relating directly to an individual included individuals not feeling able to introduce the topic of their eating difficulties; fear of being perceived negatively; not being taken seriously; or feeling that the practitioner had limited time. There was some discrepancy relating to individuals experiencing an increase awareness of their ED as part of their journey of seeking treatment; within BED, individuals reported that they often became aware independently of their eating difficulties and that HCPs more

commonly discussed concerns about physical health or weight (Evans et al., 2011; Herman et al., 2014) whereas for AN this awareness of eating difficulties was encouraged by others (Gilbert et al., 2012; Schoen et al., 2012). It is noteworthy that often individuals with AN were ambivalent to change and could be argued to be in denial about their eating difficulties, which can cause an additional barrier to disclosure and accessing treatment. Participants across a number of studies described wanting to feel better or to get rid of their depression, rather than specifically their ED symptoms; this is important to consider when taking into account ambivalence regarding treatment and also shame relating to eating difficulties (Gulliksen et al., 2015; Herman et al., 2014).

The point at which individuals' initial contact began within the healthcare system was usually at primary care level, which indicates an important part of the treatment seeking journey in which early intervention and the facilitation of disclosure could be beneficial. Individuals feeling acknowledged by healthcare practitioners may play a role in developing rapport and engagement, as will be considered in the next theme of 'interpersonal factors.' (Gilbert et al., 2012; Gulliksen et al., 2015; Schoen et al., 2012).

**Interpersonal factors.** A number of interpersonal factors were identified as being important to disclosure of eating difficulties, which link to both the internal and external factors previously discussed. Across a number of studies it was found that individuals appreciated practitioners explicitly asking questions relating to eating and initiating this conversation (Evans et al., 2011; Gilbert et al., 2012; Schoen et al., 2012). It was commonly reported that individuals did not feel able to introduce this topic of conversation due to factors already discussed: shame; lack of awareness; and fear of being perceived negatively or judged. Such qualities perceived as contributing to a positive appraisal of the disclosure process included: receiving empathy; rapport; and not feeling judged (Evans et al., 2011; Gulliksen

et al., 2015; Reyes-Rodriguez et al., 2013). Often professionals do not routinely invite individuals to share their eating concerns and this is something that should be encouraged (Evans et al., 2011; Reyes-Rodriguez et al., 2013).

**Gender.** Only one study had a specific focus on gender (Griffiths et al., 2015), however despite this limited focus of the studies, gender was identified as important theme for discussion. Gender imbalances in recruitment were not acknowledged within any of the papers that did not specify gender as an exclusion criterion. For many of these papers only female participants were recruited, but reasons for this were not considered or reflected upon. The theme of ED being a '*gendered*' disorder, primarily concerning females, has been widely documented and this is suggestive of the high number of undiagnosed EDs within the male population (Griffiths et al., 2015). This is consistent with the discovery in this review that despite only two papers having gender specific (female) inclusion criteria, six of the studies reported results from only female participants. Within studies recruiting mixed gender samples, the representation of males was limited. There was no discussion evident regarding why there was a limited number of males recruited, therefore it is unknown whether males were receiving treatment within the services and did not wish to take part or indeed whether there were no males actively engaged with the services. The lack of recognition of male EDs could be due to insufficient awareness in both the general population (e.g. individuals experiencing difficulties; friends; and parents) and by professionals (e.g. physical health investigations). Males described being fearful that they would not be taken seriously and experienced a lack of ED information, which was tailored for males or gender neutral (Griffiths et al., 2015), which could be further perpetuated by the societal view of EDs being a '*gendered*' difficulty.

## Discussion

This paper aimed to review the literature pertaining to the experience of treatment seeking for an ED within the adult population. This can be perceived as a process consisting of the following themes: social stereotypes and norms; external factors; client (internal) factors; interpersonal factors; and gender. Whilst there has been previous research into the barriers and facilitating factors, there are differing levels of emphasis and supporting evidence for these different factors. The most recent research, which has been reviewed in this paper, has explored the experience and process of treatment seeking for an ED.

Whilst the majority of the research reviewed was methodologically acceptable there are a number of considerations to be discussed. Firstly, the studies varied in terms of the methods used to screen ED for recruitment and consequently for inclusion. Five of the papers used well-validated and reliable screening measures; all but one of these used the EDE-Q self-report measure. Whilst clinical interview is identified as the gold standard for diagnosing ED, the EDE-Q self-report measure has been found to have good correspondence with the EDE clinical interview (See Appendix F for a description of the EDE and EDE-Q; Fairburn & Beglin, 1994). This correspondence and the excellent internal consistency and test-retest reliability of the self-report measure allows confidence in the EDE-Q as a screening tool. However, the remaining five studies used non-validated screening tools or relied on participants sharing diagnoses without validation using a measure or clinical interview. It is important to note that six of the studies included participants who had current or past ED diagnoses, which may have implications for the findings, as the analyses did not allow for differences between these two sub-groups. In addition, recruitment for seven of the studies were broadly across EDs and did not investigate a specific ED type; this heterogeneity combined with the variation in screening measures has implications for the reliability and validity of the findings from these studies. It cannot be ascertained whether the participants in the study would

meet the diagnostic criteria for an ED or indeed whether the findings would be generalisable and applicable across different EDs.

The terms ‘treatment seeking’ and ‘help seeking’ were often used inter-changeably to describe participants’ access to services. The lack of consistency of this term creates difficulties in determining what service or treatment was specifically being accessed in the study; for example whether this was mental health treatment; physical health treatment; self-help; or a more broadly inclusive definition. The National Institute for Health and Care Excellence (NICE, 2004) and the American Psychiatric Association (APA, 2006) stipulate that best practice for the treatment of EDs considers both the physical and psychological management of the condition, drawing upon the expertise of a multi-disciplinary team of professionals; this treatment approach is adopted internationally for EDs. In addition to the multiple treatment aspects there are also numerous different clinical settings in which EDs can be treated including: primary care services; secondary care services; ED specific outpatient services; day hospital and inpatient care, which were not determined from all reviewed studies, all of which have implications for the validity, reliability and generalisability of the research.

### **Clinical Implications**

Clinicians both at primary and secondary care level specifically asking about individuals’ eating behaviours and patterns at initial consultations may help to improve first access to specialist treatment. Facilitating this discussion and being curious about eating may expedite individuals in disclosing any eating difficulties they may have. Given that GPs are frequently the first HCP individuals disclose their eating difficulties to, this as part of the routine consultation may be beneficial for earlier detection and treatment opportunities. In addition, individuals may demonstrate some ambivalence to change; the evidence suggests that it is important that HCPs to acknowledge this within consultations and once therapeutic intervention has begun. As

advocated by guidance from the British Psychological Society (BPS), clinical psychologists should deliver training and consultation regarding these factors, including facilitating conversations, and working with low motivation and ambivalence, in order to increase awareness and ensure that this is implemented within multi-disciplinary specialist ED teams and by HCPs working within Primary Care services (BPS, 2007). The facilitation and introduction of psychological thinking at Primary Care level would allow for a proactive approach and a possible opportunity for early intervention. The balance of confrontation within the context of support and understanding is crucial within the process of problem recognition (Vandereycken and Hembreeck, 2008).

At a more idiosyncratic level, when HCPs are presented with males who may be experiencing eating difficulties it is equally important to acknowledge this and to assist dialogue about eating, as males in particular may not disclose such difficulties. This would be a step in beginning to challenge the wider societal view of EDs as being predominantly a difficulty associated with females. The dissemination of gender-specific information, aimed at males has been an issue raised relating to EDs in particular (Räsänen & Hunt, 2014).

### **Review Limitations**

Treatment seeking for EDs within a child and adolescent population was not within the scope of this review; therefore it is not known whether the principles found within an adult population would apply. Little is known about treatment seeking for EDs within this population and future research would likely yield both interesting and important findings.

As aforementioned, the heterogeneity of EDs included within this review could be perceived as a limitation, as this lack of specificity within the samples causes difficulties in making wider generalisations from the findings of the review. It is also worth noting the opposing epistemological positions concerned with the concepts studied and the

methodologies used, for example, diagnosis as a positivist concept compared to the critical realist position that many qualitative research methods hold (Willig, 2013). These differences however should not provide a significant limitation, as it is the phenomenon of treatment seeking rather than experiences relating to diagnosis that is of importance within this review.

Finally, it is important to acknowledge that this review was carried out by one independent researcher, therefore the process of selecting relevant studies for review and the synthesis of the papers may be subjective. To compensate for this potential limitation the stages of the review were describes in a detailed and transparent way.

### **Future Research**

It is estimated that in the UK, 7.9% of admissions for AN inpatient treatment are under the Mental Health Act. Since 2008 86% of ED units in England have experienced a rise in inpatient admissions under the MHA and nationally there has been a 222% increase (Sly, 2015). For example, one unit specifically reported an increase from 4% to 54% between 2008 and 2014. Research has begun to explore the reasons behind this rise and it has been suggested that this may be due to treatment being implemented too late (Elzakkers, Danner, Hoek, Schmidt, & Elburg, 2014; Sly, 2015). These increases nonetheless provide further support for the need for research to explore treatment seeking for an ED.

The majority of previous research has focused on investigating factors that promote or impede individuals' treatment seeking behaviours. Since 2010, qualitative studies have begun to explore the experiences of individuals' treatment seeking for an ED; however the exploration of the process of the treatment seeking experience is in its infancy.

This review has highlighted the heterogeneity in the populations recruited for the majority of the studies included for synthesis. Such variability included the specific EDs; whether these have been formally



diagnosed; and whether such difficulties are past or current. As a result, future research may benefit from focusing on a specific ED type, for example, BED, rather than considering the wider ED spectrum. This will allow more specificity in the application of the findings to clinical practice and has the potential to highlight differences or similarities across different EDs.

There was a marked lack of male participants within the studies reviewed; only one study specifically explored male experiences. It is interesting to consider that six of the studies reported results from female only participants; however only two studies included 'female' in their inclusion criteria. This divergence in male and female participants may be a reflection of poor awareness of male EDs (both professionally and for the individual) or an under-representation in services. Research that actively strives to recruit male participants will be integral to further understanding factors contributing to the under-representation of males within ED services (Strother, Lemberg, Stanford, & Tuberville, 2012).

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***“Suffering in silence”***

**The Experience of Treatment Seeking for Binge Eating Disorder:  
An Interpretative Phenomenological Analysis**

Paper 2 has been written with the intention of submission for publication to Qualitative Health Research; author guidelines for manuscript submission can be found in Appendix G.

The write up for this paper has used size 12 Arial font and has extended left hand margins; in accordance with the University requirements for thesis submission. All text is 1.5 line spaced unless quotations are over 40 words. For the purpose of this thesis submission additional material has been included, which will be removed before manuscript submission.

Disclaimer: This research was sponsored by Staffordshire University and conducted within a National Health Service Eating Disorder Service. The findings and discussions of this research are that of the author and may not reflect the views of either institution.

**Abstract**

It has been well documented that only a minority of individuals suffering from eating disorders (EDs) receive appropriate, specialist treatment. Research has primarily focused on investigating the factors that promote or impede individuals' treatment seeking behaviour.

Since 2010, qualitative studies have begun to explore the experiences of individuals seeking treatment for an ED; however the exploration of this process is in its infancy and to date has not been examined in Binge Eating Disorder (BED). The aim of this research was to explore the treatment seeking experience of individuals with BED, in order to increase understanding about the treatment seeking process. In particular, focusing on the potential barriers and facilitating factors in order to optimise the likelihood of individuals being able to seek treatment. Following consultation with service users regarding research design and interview question development, eight participants were recruited from a specialist outpatient ED service; all were awaiting or currently receiving psychological treatment. Data were collected using semi-structured interviews, transcribed verbatim, and analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009). Four super-ordinate themes were found: *'the self as a barrier'*; *'the overlooked eating disorder'*; *'factors contributing to treatment seeking and disclosure'*; and *'making sense of BED.'* These are discussed in relation to existing theory and research and consideration given to how these may be of use to healthcare professionals.

*Keywords:* binge eating disorder; treatment seeking; help seeking; qualitative; interpretative phenomenological analysis.

### The Experience of Treatment Seeking<sup>2</sup> for Binge Eating Disorder: An Interpretative Phenomenological Analysis

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<sup>2</sup> Existing research has frequently failed to define *'help seeking'* or *'treatment seeking'* and the terms are often used interchangeably. *'Treatment seeking'* will be used throughout this report and is conceptualised as an individual making any effort to seek professional help to address eating difficulties. All participants were waiting for or receiving psychological therapy.

Binge eating disorder (BED) is characterised by recurrent episodes of binge eating. According to DSM-5 criteria this is defined as consuming a large amount of food in a discrete amount of time with an associated sense of loss of control and is accompanied by marked distress (APA, 2013). To meet criteria for BED rather than an alternative eating disorder (ED), such as bulimia nervosa (BN), binge eating must occur without any associated compensatory behaviours, such as excessive exercise or purging (Diagnostic and Statistical Manual of Mental Disorders fifth edition [DSM-5]; American Psychiatric Association [APA], 2013). BED is associated with increased medical complications, often relating to obesity (e.g. type 2 diabetes and cardiovascular disease); distress regarding weight and shape; reduced quality of life; impaired social functioning; and psychological distress (Rieger, Wilfley, Stein, Marino, & Crow, 2005). BED was accepted for inclusion as a formal DSM-5 diagnosis in May 2013 and can now be differentiated from other EDs (APA, 2013).

Due to BED recently becoming a formal diagnosis, there is limited research in comparison to other EDs (Banker, 2013). The inclusion of BED into the DSM-5 was intended to increase awareness of the differences between BED and the more commonly experienced over-eating; BED is less common and has more associated physical and psychological difficulties (Alexander, Goldschmidt, & Le Grange, 2013). Whilst obesity is not a criterion for the diagnosis of BED, they are often grouped together and associated by both individuals and professionals. Associations have been found between BED and obesity; however, the direction of the relationship has not been defined (Striegel-Moore & Franko, 2008).

BED has been reported to be more common than anorexia nervosa (AN) and BN (Hudson et al., 2007; Iacovino, Gredysa, Altman, & Wilfley, 2012), yet fewer than half of individuals with BED receive treatment (Hudson et al., 2007). BED affects 3.5% of women and 2% of men in the United States (US); however there is currently insufficient



data available to determine country-specific prevalence outside of the US (Hudson et al., 2007). The estimated prevalence for people in the United Kingdom (UK) with an ED is 1.6 million, with 46% thought to be suffering with BED (b-eat, 2015). This is likely to be an underestimate due to reliance on data only from those accessing services (Joint Commissioning Panel for Mental Health, 2011).

### **Treatment Seeking**

It is well established that few individuals with an ED receive treatment and that there is a large unmet need within the community (Hart, Granillo, Jorm, & Paxton, 2011). The World Mental Health Survey found that a substantial proportion of individuals receive treatment for emotional rather than eating specific difficulties (Kessler et al., 2013). The average delay in receiving ED treatment has been reported to be approximately four years after onset; such delays in treatment have been associated with poorer outcomes, therefore it is essential that timely specialist treatment is received (Reas, Williamson, Marin, & Zucker, 2000; Rosenvinge & Klusmeier, 2000).

Barriers have been identified that may hinder the identification and acknowledgement of EDs and access to treatment. These include shame and denial of the illness in individuals with bulimic type EDs (Meyer, 2001; Hepworth & Paxton, 2007); concerns about negative judgments from others or perceived stigma (Goodwin & Fitzgibbon, 2002); and poor knowledge about ED symptoms and treatment (Becker, Franko, Nussbaum, & Herzog, 2004). Individuals with EDs are often perceived negatively by the public, who believe these disorders are self-inflicted (Crisp, 2005; Stewart, Peel, & Schiavo, 2006)

Facilitating factors have also been identified, which serve as prompts for individuals to seek treatment. These include: an increase in psychological distress as a result of eating difficulties; perceived symptom severity (Hepworth & Paxton, 2007); others initiating the process (Gilbert et al., 2012); increased awareness of the impact of

ED (Schoen et al., 2012); interference with everyday activities (Hepworth & Paxton, 2007); encouragement from friends and family; and self-management no longer being effective (Thomson, Hunt, & Issakidis, 2004).

Since 2010, qualitative approaches have begun to explore the processes of treatment seeking in Anorexia Nervosa (AN) and for college students with an ED (Schoen et al., 2012). When seeking treatment there was an experienced shift from denial to awareness and an increase in the ED's perceived impact. This was influenced by prior experiences and the individual's attitude towards treatment. Effective communication skills in professionals, high levels of ED knowledge and a broad range of treatment goals in addition to recovery, were identified as important for women with AN (Gulliksen, Nordbø, Espeset, Skårderud, & Holte, 2015).

## **BED**

Research into treatment seeking within BED has focused on physicians' understanding and awareness and women with bulimic type EDs attending primary care (Evans et al., 2011; Supina, Herman, Frye, & Shillington, 2016). The experience of the individual seeking treatment specifically for BED has not yet been explored. Fewer than half of individuals with BED have received treatment and the reasons for this remain unclear (Hudson et al., 2007). Individuals' experience of BED and treatment has been explored in individuals with a mixed sample of self and DSM-5 diagnosed BED (Herman et al., 2014). Only half of individuals reported becoming aware of BED through their healthcare provider and healthcare professionals (HCPs) were reported to have a greater focus on physical health; most commonly obesity, rather than on their eating difficulties. Individuals experienced multiple barriers when interacting with HCPs, these included: shame related to eating; professionals having limited time; and professionals attributing BED to controllable overeating. Given the limited research focusing on BED and its recent recognition in the DSM-5 as a separate

ED, a qualitative approach is warranted to provide rich and detailed information regarding the complex process of treatment seeking for BED.

### **Research Aims**

This study aims to explore participants' lived experiences of treatment seeking for BED. This includes facilitating factors and barriers, in order to further understand the process and to optimise the likelihood of other individuals seeking treatment in the future.

### **Research Question**

How do adults experience seeking specialist psychological treatment for binge eating disorder?

## **Methodology**

### **Ethics**

Independent peer review approval was gained from Staffordshire University (Appendix H). Greater Manchester West National Health Service (NHS) Research Ethics Committee gave the research favourable opinion (Appendix I) and Research and Development (R&D) approval was secured from two NHS sites<sup>3</sup> (Appendix J).

### **Participants**

Eight participants were recruited from an outpatient ED service in an NHS Trust between May and December 2015. All participants were awaiting or receiving psychological treatment. Inclusion and exclusion criteria are listed in Table 1. Basic demographic information for participants is shown in Table 2.

Table 1

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<sup>3</sup> R&D approval was sought from two NHS sites; recruitment was not successful from the second NHS site, when sufficient numbers had been recruited from the first NHS site recruitment ceased at both sites.

*Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
Over 18 years old	Diagnosis of AN or BN
DSM-5 diagnosis of BED	Recent suicide attempt (< 6 months)
Currently attending a specialist ED outpatient service	Unable to speak English

*Note.* AN = anorexia nervosa; BN = bulimia nervosa; BED = binge eating disorder; DSM-5 = Diagnostic Statistical Manual of Mental Health Disorders; ED = eating disorder.

Table 2

*Participant Demographic Information*

Demographic Information		
Gender	Female	8
	Male	0
Body Mass Index (BMI)*	Mean	36.9
	Range	26 – 48.4
Duration since Diagnosis	Mean	2 years
	Range	7 days – 10 years
Ethnicity	White British	8
Marital Status	Married	3
	Single	4
	Separated	1
Occupation	Full time	4
	Part time	2
	Unemployed	1
	Student	1

**Body Mass Index (BMI)**

BMI is a representation of weight adjusted for height and is calculated by dividing an individual's weight by the square of their height (National Obesity Observatory, 2009). An advantage of the use of BMI as a measure is that there is availability of public thresholds to which BMIs can be compared. It is generally accepted that a BMI below 18.5 is considered to be underweight, between 18.5 and 24.9 within the healthy range, 25.0 to be overweight and 30.0 within the

category of obese. Data from the Health Survey for England (2015) identified that in 2014 approximately 25% of adults were obese (BMI 30.0 or above). Being overweight was more common than obesity with 41% of men and 31% of women being overweight. Some of the physical health risks with having a BMI of 30.0 and over include cardiovascular disease; gall bladder disease; hypertension; and type-two diabetes (Centers for Disease Control and Prevention, 2015). There are however some limitations with the use of BMI as a measure as factors such as: muscles mass; ethnicity; body fat distribution; and puberty, which can have an impact on the relationship between body fat and BMI.

### **Recruitment and Procedure**

Members of the clinical team approached potential participants and those meeting inclusion criteria were given a Letter of Invitation and Participant Information Sheet (Appendix K). If interested, the individual gave a preferred contact to a member of the clinical team. All participants were required to give both verbal and written informed consent (Appendix L).

The National Institute of Health Research (2013) advocates for the involvement of individuals with lived experience of mental health difficulties to be included in research design and development, in order to ensure that studies are both relevant and meaningful. Therefore service user (SU) involvement was gained during the development of the research design and the interview schedule (Tait & Lester, 2005) (Appendix M). The final interview schedule was developed following discussion with a Clinical Psychologist and ED Research Fellow, questions included: *How do you feel professionals view binge eating? What was the most valuable factor that encouraged you to seek treatment?* Questions were broad to ensure that the researcher did not impose their understanding on to the participants' narrative (Smith, Flowers, & Larkin, 2009).

All interviews were audio recorded and transcribed verbatim by the researcher on NHS premises. To protect anonymity pseudonyms were used and staff names and other identifying information were substituted. Interviews ranged from 40-66 minutes and were conducted in clinical rooms within the ED service. All documentation was kept in a secure cabinet and transcripts were stored on an encrypted memory drive.

### **Analysis**

Due to the exploratory nature, Interpretative Phenomenological Analysis (IPA) was used (Smith et al., 2009). This is a qualitative methodology, which focuses on the processes through which participants make sense of their experience. It is based on the ideology that there is no direct way to access a person's lived world and that this is only possible through their individual meaning-making and the use of language shared with the researcher. It is phenomenological as it attempts to understand a particular phenomenon from the participant's perspective. IPA recognises that the access to a participant's experience depends on what they share and how the researcher then interprets this. This is referred to as the double hermeneutic, in which the researcher is trying to make sense of the participant making sense of their experience.

Data collection and analysis followed the guidelines outlined by Smith et al. (2009); it was an iterative and inductive cycle. The first step involved the researcher becoming immersed into the data, which meant that transcripts were read, whilst listening to the audio file in order to understand each participant at a deeper level. The researcher's initial thoughts were recorded to ensure that the researcher began to enter the participants' world. Line by line coding was carried out; different colour ink was used for the descriptive, linguistic and conceptual comments (Appendix N). Following this extensive process, emergent themes were noted. The emergent themes were then compiled in chronological order into a separate

document (Appendix O); these were then clustered to map out the interrelationships and patterns between the emergent themes (Appendix P). Connections were determined using abstraction, polarisation, contextualisation, numeration and function (Smith et al., 2009). These were then recorded in a table, detailing the transcript line numbers from the extracts and repeated for each case (Appendix Q). Patterns were identified across participants, which led to the development of super-ordinate and sub-themes (Appendix R); these were recorded within a master table of themes. This ensured quality as it produced an independent audit trail as recommended by Yin (1989). Yardley's (2000) four criteria for assessing quality were used to evaluate the research.

### **Epistemological Position and Reflexivity**

A reflective diary was kept, which included reflections on SU involvement, recruitment and responses following interviews, allowing contextualisation. In addition, the researcher kept up to date with media coverage regarding over eating and obesity, which provided cultural resources to help make sense of the data (Hollway & Jefferson, 2005).

The researcher is a 26 year old, white British female, working as a Trainee Clinical Psychologist within an NHS setting. The researcher has an interest in EDs and has previously held a research assistant position within an ED service. The researcher understands EDs within the context of a biopsychosocial model, in which eating difficulties occur as a result of emotional distress. EDs are understood as being on a continuum, with a preoccupation with shape, weight and food being the central concern; this transdiagnostic approach does not rely on a specific diagnosis for formulation or intervention (Fairburn, Cooper, & Shafran, 2003).

The researcher is female, which may have reinforced the widely held belief of EDs being a predominantly female difficulty. The researcher was aware of her gender, appearance and professional

role, and how these similarities and differences may have had an influence on data collection, analysis and interpretation; this is in line with the researcher's epistemological position of critical realist (Willig, 2013). Many participants expressed wanting to be a '*normal*' weight, which after further exploration meant being a '*healthy*' weight. Given that the researcher is of an objectively healthy weight, this may have had an impact on what participants shared during data collection. The extent to which the researcher impacted on the dialogue and what was shared within the interviews cannot objectively be determined. The Johari window of self-awareness in interpersonal relationships is a useful tool to aid reflection regarding the researcher's 'blind spot'; this refers to what is known about an individual by other members of a group or individuals, but is not known by the individuals themselves (Luft & Ingham 1955). Within this area self-awareness can be increased by seeking feedback from others, this was done at the end of each interview and also in peer and research supervision. In addition there is the area of the 'unknown', this refers to information and feelings that are not known to the self or to others but can have an impact on behaviour, therefore it is important to be mindful of this possible unconscious influence.

### **Analysis Credibility**

Initial coding, emergent themes and super-ordinate themes were checked by members of the research team, which included a researcher specialising in qualitative research methods and a clinical psychologist working within EDs (Yardley, 2000). To further ensure rigour, on-going analysis was discussed regularly within a specialist IPA group. Any discrepancies were discussed and this led to the rearrangement and re-naming of superordinate themes.

### **Results**



The analysis aimed to describe participants' experiences, considering both convergences and divergences in a coherent narrative. Four super-ordinate themes and 11 sub themes were identified (Table 3). All sub-themes were interlinked; however to provide clarity they will be discussed individually. A diagrammatic representation of the themes can be found in Appendix S.

Table 3

*Super-Ordinate and Sub-Ordinate Themes*

Super-Ordinate Theme	Sub-Ordinate Themes	Participants Present:
1) The self as a barrier	<ul style="list-style-type: none"> <li>The self as worthless</li> <li>Comparing the self to others</li> <li>Shame: <i>"putting on a mask"</i></li> </ul>	<p>3, 5, 6, 4, 7, 8</p> <p>3, 7, 2, 8, 5, 6</p> <p>2, 5, 6, 7, 4</p>
2) The overlooked eating disorder	<ul style="list-style-type: none"> <li>Lack of awareness</li> <li>Societal stereotypes of obesity</li> </ul>	<p>3, 2, 1, 5, 8, 7, 4</p> <p>3, 2, 8, 5, 6, 4</p>
3) Factors contributing to treatment seeking and disclosure	<ul style="list-style-type: none"> <li>Awareness and acceptance</li> <li>Critical incidents</li> <li>Interpersonal characteristics</li> </ul>	<p>All participants</p> <p>All participants</p> <p>3, 1, 5</p>
4) Making sense of binge eating disorder	<ul style="list-style-type: none"> <li>Psychological impact of diagnosis</li> <li>Understanding the self</li> <li>The future self</li> </ul>	<p>3, 2, 1, 4, 6</p> <p>3, 8, 6, 7, 2, 4, 5</p> <p>3, 8, 5, 7, 4</p>

Participants' accounts suggested that they had all experienced difficulties in their journeys to access specialist treatment. Participants had all attempted to seek help several times without success, before receiving treatment for their ED from professional services. Specific

difficulties in accessing treatment, as outlined by the theme '*the self as a barrier*' were interpreted as being a central process. An example was participants' identification of the self as not being worthy of treatment; social comparison; and the shame attached to eating difficulties. This theme was reinforced by contextual factors, which appeared to further impede access to treatment; this was described in the theme of '*the overlooked eating disorder*.' Facilitating factors, including the interpersonal factors contributing to feeling understood; the process of awareness; and critical incidents, as described in the theme '*factors contributing to accessing treatment*' led participants to feel able to initiate the treatment seeking process and to disclose their difficulties. Finally, '*making sense of BED*' as a consequence of accessing treatment was identified; this was encompassed within the themes of the psychological impact of receiving a diagnosis of BED; the value of psychological formulation in understanding the self; and the future self.

### **Superordinate Theme One: The Self as a Barrier**

A range of experiences related to the self as a barrier to treatment seeking. These subthemes were: identifying *the self as worthless*; *self-comparison*; and *shame*, which led to participants '*wearing a mask*.'

**The self as worthless.** A negative sense of self and feelings of worthlessness were experienced as barriers to attending appointments within a specialist service. There was an identification of personal control and responsibility for eating difficulties and therefore help was perceived as a 'privilege', which was not deserved:

*"I was referred ... and then I cancelled, because I didn't think I was worth it. ... It wasn't justifiable. I felt I was using up valuable time. I thought it is your own fault, you're overweight it's your fault, you control what you put into your mouth, why should you have the privilege of help."*

Participant 3; line 14 – 16

Feelings of not being deserving of help were underpinned by an overwhelming negative sense of self for almost all participants. Many identified themselves as a '*fat person*' and based their identity on their external, visual appearance. Participants judging themselves in a negative way and subsequently expecting this from other people links to the theme of the internalisation of societal stereotypes:

*"It is so obvious because you wear it, people can tell that you're not managing your life when you're wearing the fat on you, you know what I mean, its just so visual isn't it."*

Participant 6; line 409 - 410

**Comparing the self to others.** A common narrative was making social comparisons to others, in particular comparing the self to people with other EDs. This led to a minimisation of difficulties in comparison, which may have further reinforced the perception of the self as not worthy of treatment:

*"I have a sister who has suffered from bulimia and anorexia and I have you know seen the states she has been in and I think actually I am not as serious as someone like her ... I didn't think it was appropriate for me."* Participant 3; line 110 - 114

Participants also experienced other people making comparisons about them, which led to an expectation of being treated in a different way to

people with other EDs. This created feelings that the severity of their difficulties were belittled:

*“The nurse said everyone binges so in a way that normalises it but it says well anorexia and bulimia are severe and everyone binges. Maybe I should just go back and say actually I have started to make myself sick.”*

Participant 7; line 388 - 390

Differences in physical state (*the visible*) between EDs were experienced, however participants also experienced similarities in their mind set (*the invisible*), which are not recognised by others:

*“People don’t think it is a problem ‘cos you don’t look unwell. I did look healthier but my mind was worse, bingeing isn’t healthy, no one realises it’s a problem because they can’t see it.”* Participant 5 line 32 - 35

One participant oscillated between experiencing all EDs as being on an equal continuum and feeling different from other EDs. This differentiation was identified as being able to function physically and therefore needing to cope alone. Professionals, at times, reinforced these feelings of difference:

*“I had friends with the more serious eating disorders, anorexia and bulimia, who were physically ill and had hospital admissions ... I understood it as part of the same continuum, I understood intellectually but actually it wasn’t ... I could go to work and I could have my social life. I could function physically ... pull yourself together.”*

Participant 2; line 89 - 92

*“Are you making yourself sick was the first thing they asked, first thing they jump to. I had to explain why I wasn’t.”* Participant 4; line 45 - 46

**Shame:** “*putting on a mask.*” Intense feelings of shame about binge eating behaviours were experienced, which resulted in participants’ attempting to keep their difficulties a secret; “*it was my thing*” (Participant 4), “*my dirty secret*” (Participant 6):

*“Everyone thought I was eating really healthy and everyone thought that about me, but I wasn’t. I wanted everyone to think I was eating healthily so that drove me to keep it a secret.”* Participant 4; line 146 - 147

The need to keep binge eating a secret led to an internal conflict as participants experienced incongruence between their internal and external worlds:

*“It is extremely private, it is probably my worst secret, I couldn’t possibly have anyone knowing about it. I am a master at hiding it and coming across as together.”*  
Participant 7; line 201 - 202

Participants described how they worked hard in ‘*putting on a face*’ (Participant 6) to other people in their lives, this allowed them to cope with their difficulties and to continue functioning:

*“I think that that mask or whatever has kept me putting on a face that has been able to keep me going, I think it’s acting isn’t it.”* Participant 6; line 174 - 175

When wearing a mask became too hard, a critical point was reached and this prompted seeking treatment. There appeared to be a difficulty in articulating what ‘*losing the plot*’ would mean, which could defend against an underlying fear of not being able to ‘*keep up the mask*’:

*“What I have found of late is that it is getting harder to wear and that’s where I am struggling ... I have always said if I couldn’t keep that mask up at work then I would lose the plot. I think I would be on a, on a circle really of*

*... I don't know if I could get back."* Participant 6; line 177

- 179

### **Superordinate Theme Two: The Overlooked Eating Disorder**

The concept of binge eating as being overlooked contributed to attempts of seeking treatment with no success. These subthemes included 'a lack of awareness' and 'societal stereotypes of obesity.'

**Lack of awareness.** All participants experienced either feeling misunderstood or that their eating was not acknowledged by HCPs; this was attributed to a lack of awareness of BED. Depression was acknowledged and at times eating difficulties were all attributed to depression:

*"I wish I had tried to get help sooner, but I think I have actually, I say look I am struggling with this or whatever and it has always been deemed as depression so it's always under the band of depression, but I don't think it was, or is."* Participant 6; line 77 - 79

Frequently, weight loss was central in consultations with professionals:

*"You need to get your weight down because of your other health issues, that's what I always get chucked in my face by professionals. Keep your weight down, get your weight off."* Participant 1; line 111 - 112

This relationship between not feeling understood and not accessing treatment was bi-directional; participants were not aware of their eating difficulties nor that there were services they could access for help with their eating:

*"People who are suffering with it, don't know that it is there and that it actually is a problem, I had to find out for*

*myself and that was because I looked it up and typed in my behaviours.”* Participant 4; line 118 - 120

*“I know to a point people won’t accept help unless they are ready. But if they knew it was out there and it wasn’t as scary as they think, maybe more people would go and get the help.”* Participant 1; line 288 - 289

Experiences of not being understood and taken seriously by professionals evoked a sense of hopelessness for the future and reinforced feelings of worthlessness and thoughts that they were not deserving of help, as discussed in the ‘*the self as a barrier*’. This was attributed to physical appearance:

*“He said is it stopping you doing things, and I said not really, which wasn’t true, because of his attitude I thought I am not going to get anywhere with this and he said go away and do some exercise [laughs], it is not visible in the way certainly as it is for low body weight.”* Participant 2; line 67 - 69

As a result of feeling misunderstood, many participants felt that they were not being taken seriously and that their difficulties were minimised. Feeling dismissed led to the internalisation of difficulties and feelings of inflated responsibility and self-blame:

*“You go to the Doctors and they would say it is what goes in to your mouth that causes the problem, simple ... You kind of think well yeah I know if I cut down what I am eating I will lose weight, they weren’t understanding that I had no control ... I felt stupid.”* Participant 3; line 304 – 306.

**Societal stereotypes of obesity.** Awareness of stereotypes surrounding obesity was an integral theme, which contributed to the

theme of binge eating being experienced as an overlooked and dismissed ED:

*“You know large, obese people, you hear people say why are they shoving all that food in their mouths, how can they eat that much, they’re greedy I think to myself they have got BED too.”* Participant 5; line 294 - 295

The obesity stereotype experienced by participants may perpetuate the lack of awareness and identification of BED by wider society, professionals and participants:

*“It is what you see on TV, how obese people are costing the NHS and this and that when some people have problems controlling their eating and that’s an illness but people stereotype.”* Participant 8; line 343 - 344

Internalisation of these stereotypes led to self-identification based on external appearance. Participants used self-derogatory words based on the physical self such as ‘fat’ ‘obese’ and ‘massive.’

*“Fat, lazy and useless, you know that kind of you must be fat lazy and useless and that goes back to the stereotype of fat people and it compounded that.”* Participant 6; line 168 - 169

Although some participants internalised the stereotypical views of obesity, this was not the case for all participants. The use of words such as ‘they’ and ‘their’ indicated distance between themselves and individuals discussed within popular media, which may play a protective role:

*“Any media coverage is all about what they are eating, too much of this, too much of that, too much fat, too much sugar, it is their own fault, they should exercise more.”*  
Participant 3; line 119 - 121



Participants described feeling hyper-vigilant to obesity being ostracised in the media and the impact of this was a further deepening of feelings of shame, self-blame and being a burden:

*“I really hate it, fat shaming, I feel like it has been going on for a long time, I have been really sensitive to it ... I feel shame and guilt and you know I am taxing the health service beyond its services.”* Participant 2; line 417 - 418

### **Superordinate Theme Three: Factors Contributing to Treatment Seeking and Disclosure**

This theme describes the various factors that participants identified as catalysts to accessing treatment. These factors were related to facilitators for recognising the need for professional help and then the actual disclosure of eating difficulties.

**Awareness and acceptance of binge eating.** Growing awareness of binge eating becoming a problem was central to treatment seeking:

*“I kind of thought you know this is all, you know, this is actually a psychological problem and I am depressed and I am being treated for that so maybe I could get some help for this.”* Participant 2; line 145 - 147

For some participants the denial of their eating difficulties could be seen as a psychological defence, which was used as a coping mechanism:

*“I went through a phase of trying to convince myself that I just liked food and I just eat more than anyone else because I like to eat and I am happy. It wasn't true but I think I convinced myself enough to carry on.”* Participant 2; line 84 - 86

This avoidance could be a conscious decision to not actively think and talk about binge eating. For others, difficulties with binge eating was not initially in their awareness, which links to the sub-theme of '*critical incidents*'. This was a perceived loss of control over eating, which shifted their eating difficulties into their awareness:

*"I didn't actually seek help because I didn't realise I had a problem, then I couldn't stop basically and it was worrying me."* Participant 5; line 211 - 212

The process of sharing one's difficulties allowed participants to feel accepted by others and by other people, which in turn encouraged them to be able to seek support:

*"I feel lucky that I was given the support by my family to come forward for the help ... This is me, this is who I am, accept me or don't."* Participant 3; line 29 – 31

**Critical incidents.** A striking element of experiences of treatment seeking was frequently related to a critical incident, which had an impact on the participants' life role. This was expressed as reaching the point of '*I can't do this anymore*' (Participant 4) and experiencing increased desperation and distress. Participants described attending primary care services. Whilst this was not always specifically related to eating difficulties, these were discussed as a consequence:

*"I was like jeeez, I have had enough of this fat thing... I had enough, everyone is having a band, take my stomach away [laughs] ... I am sick of fighting this battle and losing."* Participant 6; line 318 - 219

Participants described a shift in responsibility within their own life roles, for example, becoming pregnant and therefore feeling responsible for others:

*"I know when I was pregnant I was still going to Weight Watchers but I was bingeing everyday and I was concerned about what it was going to do to her."*

Participant 7; line 289 -291

**Interpersonal characteristics.** All participants identified key characteristics in professionals that encouraged disclosure; these included being supportive, showing a genuine interest, being non-judgmental, active listening, being informative and personable:

*"I was grateful that it had actually been acknowledged and someone was actually listening to me. That I wasn't being judged and people understood. I felt judged before." Participant 1; line 90 - 92*

Participants favoured attributes in professionals that allowed them to feel equal; such identification facilitated feeling understood and liberated after a period of time:

*"[name] was very down to earth and that was a relief .. I was made to feel an equal, there was the empathy ... she genuinely cared and was taking an interest and wasn't dissing what I was saying." Participant 5; line 191 - 192*

In addition to active listening and feeling understood, a professional directly asking about eating habits was experienced as a valuable facilitator to the disclosure process:

*"She was understanding, listened to me and asked me about my eating habits and then she thought it would be useful to refer me here. It is thanks to that, I wouldn't have voluntarily asked for help." Participant 3; line 199 – 201*

Professionals who made a referral to specialist services often instigated the recognition of eating difficulties. It was a commonly

shared experience for participants to have attended a General Practitioner (GP) appointment for reasons other than eating concerns. It was through this initial conversation that some participants became aware of their eating difficulties. Use of words such as *‘they decided’*; and *‘they felt’* indicated a passive role in the process and an experience of a power imbalance, with participants identifying the professional as the knowledgeable expert:

*“I went to my GP and we were talking my weight and she felt it wasn’t normal eating habits, I didn’t identify with this before that ... Then they decided, that they felt I needed to address my eating.”* Participant 8; line 11 - 12

#### **Superordinate Theme Four: Making Sense of BED**

Participants described experiences of making personal sense of their eating difficulties as a result of accessing treatment.

**Psychological impact of diagnosis.** All participants experienced an emotional reaction in response to receiving a diagnosis of BED; for all but one of the participants this was experienced as being positive and validating:

*“Once you get the letter that stated I had the binge eating disorder and that it was not my fault, that was kind of a like huge relief that I wasn’t wasting someone’s time and that there was a genuine need for me to come.”*

Participant 3; line 42 - 44

Participant 3 made use of the word *‘the binge eating disorder’*; for some participants the diagnosis meant that the blame was remitted and their difficulties could be externalised and located within the disorder rather than the self. The diagnosis provided an internal model of their eating difficulties and enabled participants to make sense of difficult past experiences. They were receptive to psychological ideas

and were able to begin to '*understand the self*' as discussed in the next subtheme. Receiving a formal diagnosis challenged participants' negative sense of self and provided them with validation for receiving treatment:

*"At least I can say that I have been diagnosed with an eating disorder so I am justified in being here."* Participant 2; line 386 - 387

This caused conflict, as whilst the diagnosis challenged participants' sense of self and provided them with validation, they felt unable to share this with others. Some participants did not take their current difficulties seriously and receiving the diagnosis challenged this view; the consistent light-hearted attitude could play a protective role, which could be understood and interpreted as denial:

*"The diagnosis has shaken my world, my beliefs and my perceptions but I cannot talk about it. I remember walking in and saying not bulimic am I, being really flippant. I feel that this is really significant since coming last week [receiving diagnosis] but I don't feel able to talk about it without being flippant."* Participant 6; line 501 - 503

There was frustration at the perceived delay in receiving a '*proper*' or '*formal*' diagnosis. Some participants considered how things might have been different if they had received a diagnosis earlier. There was a process of acceptance; during the interview Participant 6 went through a transition of rejecting the concept of BED to accepting an ED:

*"I feel like it isn't a proper diagnosis that it isn't a proper illness and that I am being dramatic, ... get a bloody grip, sort your head out ..." ... "I am already thinking that I have*

*got an eating disorder and that I am going to discover that I have had it a long time.”* Participant 6; line 456 - 458

Importantly, diagnosis normalised participants’ experiences and contributed to development of the belief that recovery is possible and provided hope for the future. This is discussed in more detail in the subtheme of *‘the future self.’*

*“I felt like a huge weight had been lifted off my shoulders, because it wasn’t, there was something that could be treated, it is not just me.”* Participant 3; line 77 - 78

For one participant however, the experience of receiving a diagnosis was not positive and they felt depersonalised:

*“I was angry at first when I got told that, before I had a problem with food and now it had a label.”* Participant 1; line 81 - 82

**Understanding the self.** Many participants experienced positive effects of making sense of their eating difficulties and beginning to make links between life experiences and current struggles through a process of self-discovery:

*“I equate my binge eating now with being really stressed, so if I feel like I need to eat all of the time, I know I need to look at why.”* Participant 4; line 21 – 23

When professionals placed emphasis on the emotional and psychological aspects of binge eating and began to create the foundations for a ‘formulation’ or an explanation of their difficulties, this helped participants to begin to understand the self:

*“I hadn’t really thought about how I felt, they were asking how I felt when doing it and what led up to it. That was*

*important for me that they took the time to ask how I was feeling.”* Participant 5; lines 44 - 45

Participants highlighted that they wanted the wider context of their difficulties to be considered, rather than focusing solely on concerns with the ‘visible’ external weight:

*“Not them keeping saying get your weight down, look at the problem, look at the bigger picture.”* Participant 1; lines 99 - 100

For one participant making links between life events and current difficulties was perceived as unhelpful and irrelevant. These connections were experienced as forced rather than being collaborative:

*“They have tried to pin point some issues, like they were trying to say it was because of my mum having cancer... they were trying to pin point something that was not relevant.”* Participant 5; lines 267 -266

**The future self: optimism and hope.** Participants moved from a state of hopelessness about the future, to feeling optimistic about the possibility of recovery and were grateful for the referral. The negative sense of self, as discussed in the theme of ‘*the self as a barrier*’, and lack of awareness of services contributed to such hopelessness for the future. The referral process created feelings of relief and triggered a shift in participants’ perceptions of the future self, by challenging their feelings of not being worthy of help:

*“It has given me a bit of hope, the thought of working towards change has given me hope for the future.”*  
Participant 8; line 340 - 341

The process of feeling both understood and supported continued to be the catalyst for optimism; this provided participants with validation that this is not a '*chosen*' behaviour; therefore challenging self-criticism. The therapeutic environment, rather than the psychological intervention received, was important for all participants in evoking hope.

### Discussion

The aim of this research was to gain an in-depth understanding of adult's experience of seeking psychological treatment for BED. The findings were interpreted to highlight four super-ordinate themes: *the self as barrier; the overlooked eating disorder; factors contributing to treatment seeking and disclosure; and making sense of BED*, which may all interact in a complex way to impact on treatment seeking. Few studies have examined the treatment seeking process for EDs using qualitative methods and to the best of the author's knowledge this is the first to have explored this within a BED sample. Exploring treatment seeking for BED will make an important contribution to the existing knowledge base for BED, which to date has primarily used quantitative research methods to explore epidemiology and treatment outcomes. This research also provides new theoretical insights that might assist clinicians in effectively engaging and encouraging individuals to seek treatment for BED.

### Theoretical Implications

There are a number of salient psychological theories and concepts underpinning the themes in this study. These include: shame; self-compassion; denial; and social identity theory.

**Shame.** Participants identified intense feelings of negativity towards the self and feelings of worthlessness, which led to the belief that treatment was not deserved. The findings have offered new insights into how participants make comparisons of the self to other EDs, which appeared to perpetuate such feelings of worthlessness.



Such comparisons can be explained by the underpinning theory of Social Comparison (Festinger, 1954).

As a result of '*putting on a front*' participants often described feeling incongruence between their internal and external worlds; this experience could be explained by the psychological concept of shame. This shame often prevented them sharing their difficulties with others; including HCPs. Within the ED literature, shame has been identified as having a maintaining role and in particular, the experience of shame associated with binge eating is important in facilitating clients to understand their experiences (Gilbert, 2007; Swan & Andrews, 2003). Shame can be understood as a self-conscious and socially focussed emotion in which the self is seen as flawed or inadequate in some way; this is caused by a sense of behaving in a way that is not acceptable by an individual (Tangney, 1995). Participants' feeling not worthy of treatment and fearful of negative judgement from others can be explained by this experience of shame and negative evaluation by the self and/or others. Such judgement of the self can leave individuals feeling vulnerable and powerless, which can further impede the belief that the self is worthless (Tagnery & Dearing, 2002). It has been suggested that shame can diminish positive emotions, therefore making it one of the most painful emotions to experience (Gilbert, 1998). It has been suggested that shame may be influenced by culture; individualistic cultures may promote shame as a stable sense of the self due to the cultural emphasis on independence and of the self; as a result shame is then kept hidden (Wong & Tsai, 2013).

**Self-compassion.** Negativity towards the self and feelings of worthlessness can be further interpreted and understood by low self-compassion (Gilbert, 2005). Self-compassion may play a protective role against both shame and in the development of eating difficulties (Magnus, Kowalski & McHugh, 2010). This is consistent with understanding the participants in this study to have low self-

compassion, as experiences of both shame and eating difficulties were described.

Compassion Focused Therapy (CFT) has been specifically developed in order to address shame and self-criticism by facilitating self-compassion (Goss, 2010). This therapy developed from the idea that individuals who are high in both shame and self-criticism have difficulties in generating warm and affiliate inner kindness towards the self (Gilbert, 2005), which could explain the negativity towards the self that participants experienced.

Self-compassion has been defined as an attitude of kindness and warmth towards one's own personal distress and disappointments (Gilbert, 2005). This has developed from Gilbert's (2005) model of affect regulation, which suggests that criticism and hostility from the self and others stimulates the threat system, which includes feelings of anxiety and shame. As a result the soothing system is activated, which includes warmth and compassion and produces feelings of calmness and safety and regulates the threat system. Individuals who have had difficult early experiences may be prone to developing shame due to threat systems being overactive and their soothing systems underactive; as previously discussed, shame may then be triggered and maintained by the belief that the self is flawed. Bingeing and purging have been noted as attempts to regulate shame, and as found in this study, the experience of secretive behaviours such as bingeing can perpetuate the belief that one is different (Goss & Gilbert, 2002; Goss & Allan, 2009). As self-compassion increases it is proposed that shame and ED symptoms may decrease (Kelly, Carter & Borairi, 2014). Whilst it is not possible to ascertain from this study whether there were any changes in experiences of shame it could be hypothesised that individuals began to experience an increase in self-compassion and understanding following access to specialist services and feeling listened to and validated.

**Denial.** The process of becoming aware of one's difficulties was experienced as a facilitating factor for treatment seeking; whilst this is consistent with existing literature for AN this is the first time it has been found within the BED population (Schoen et al., 2012). This was interpreted as a shift from denial into awareness; when binge eating was identified as problematic (Hepworth & Paxton, 2007).

Freud (1894; 1896, as cited in Howard, 2010) suggested that individuals have ego defences, which are triggered when under threat in order to protect the self from unwanted painful emotions such as anxiety and guilt. Denial is a defence that could be used to explain participants not recognising and acknowledging their eating difficulties to the self and/or to others. Denial can serve a protective function as it can block events from an individual's awareness and thus protecting them from internal distress. Denial is a multidimensional concept and has proven difficult to define due to the need to collect information retrospectively, because of individuals needing to acknowledge and disclose their difficulties. Two major categories of denial have been distinguished (Vandereycken, 2006): unintentional denial, a neurobiological impairment of self awareness and information processing; and 'deliberate denial' which services as an avoidance of feared consequences or a refusal of self-disclosure, which is commonly experienced within EDs. This interpretation of denial as 'not admitting' and 'faking good' provides as explanation for many of the participants who described putting on a front and feeling shameful of disclosure due to: society's view of binge eating and obesity; fear of negative judgement from the self and others; and self comparison. This experience can be underestimated by clinicians, who may be unaware of the interpersonal context of denial that they are involved with (Vandereycken & Humbeeck, 2008).

**Social identity theory.** Shame was experienced regarding eating difficulties, physical appearance and weight; this was

interpreted as being perpetuated by the societal views of obesity, which were then internalised. This internalisation can be explained using social identity theory (Tajfel, 1979), which proposed that the groups people identify themselves give them pride and self esteem, which contributes to their sense of social identity. Individuals therefore self-stereotype and categorise the self in line with widely held stereotypes associated with these groups. This then forms part of the self concept and can have a positive or negative influence on self esteem (Hogg & Abrams, 1990).

In this study the majority of the individuals described identifying themselves as a member of a stigmatised group; this can be interpreted as a self-stereotyping of the widely held derogatory views of obesity within society. Consistent with previous research this may have a negative impact on self esteem and therefore may have had an impact on treatment seeking (Katz, Joiner & Kwon, 2002). A model has been proposed which links perceived membership in a devalued social group with emotional well-being (Katz et al., 2002). Members of devalued groups were found to internalise negative views about themselves as individuals, which then increases the risk of depression and anxiety. The effects of personal self esteem, devaluation of one's perceived social group and attitudes are predictors of emotional health, which could be used to understand participants' experiences of stereotypes and the impact on their self esteem and psychological well being. In particular, women's perceptions of being part of a devalued social group have been found to increase their risk of depression when compared to men, which is interesting to consider in light of these findings and the feminisation of both EDs and the concept of 'fat' (Bordo, 2004).

### **Originality of the Research**

This study is the first to highlight the experience of individuals who are experiencing BED having difficulty in making the

differentiation between BED and obesity; this indicates that awareness and education is required both at an individual, within the NHS and within the wider society. Individuals described attending slimming groups; this could be an avenue that clinical psychologists could use within wider society to both raise awareness of binge eating disorder and for groups to then disseminate information and encourage treatment seeking. Emotional eating and over eating are different to BED and as experienced by participants this is not widely recognised by other individuals or professionals. In line with experiences relating to social stereotypes of obesity, Turner (2013) highlighted that information regarding BED is often discussed within the context of obesity, which could contribute to the lack of awareness. It is important to note that not all individuals with BED are obese and not all individuals who are obese have BED (Hudson et al., 2007).

An additional unique finding was the positive experience of individuals beginning to understand and make sense of BED, for example, beginning to understand the self and the development of BED. This was particularly helpful when professionals considered the wider context and made links between individuals' eating difficulties and life events. This process of making sense of one's difficulties fits with the definition of '*psychological formulation*', which aims to summarise an individual's core problems and suggest how these difficulties might relate to one another by drawing on psychological theory. It considers both the development and maintenance of difficulties as a shared narrative, which holds personal meaning for the individual (Johnstone & Dallos, 2006). Interestingly, the majority of participants experienced receiving a diagnosis of BED as being a positive and validating experience. This is pertinent given the current debates within the Division of Clinical Psychology (DCP) regarding the clinical utility of diagnoses (DCP, 2013). This research has shown that participants experienced both diagnosis and making sense of the self as integral to making sense of BED.

This study was the first to have found experiences of shame in a sample of individuals receiving treatment with a diagnosis of BED; this is consistent with findings reported in BN related to bingeing and vomiting where shame has been ascribed to self and perceived stigma from others; shame; and loss of control are commonly cited barriers to treatment seeking for individuals experiencing bulimic behaviours (Serpell, Treasure, Teasdale, & Sullivan, 1999; Serpell & Treasure, 2002; Hepworth & Paxton, 2007; Pettersen, Rosenvinge, & Ytterhus, 2008; Herman et al., 2015). This was consistent with the findings in this research; however participants also experienced shame regarding physical appearance and weight.

### **Clinical Implications**

There are several unique findings from this research; which have implications for engaging individuals with BED both within and outside specialist services.

The experience of shame associated with binge eating is important in order to help clients begin to understand and make sense of their experiences. Shame is understood as a self-conscious and socially focused emotion in which the self is seen as flawed or inadequate in some way and that it is caused by a 'conscious' sense of behaving in a way that is not acceptable or determined as 'wrong' by an individual (Tangney, 1995). Participants' feeling not worthy of treatment and fearful of negative judgement from others can be explained by the experience of shame being closely associated with being negatively evaluated by the self and/or others. Such judgement of the self can leave individuals feeling vulnerable and powerless, which can further impede the belief that the self is worthless (Gilbert, 2007). Recently it has been proposed that shame may be influenced and determined by culture; individualistic cultures may promote shame as a stable sense of the self, due to the cultural emphasis on independence and the self, therefore shame is kept hidden (Wong & Tsai, 2013).

Within the ED literature shame has been identified as having a maintaining role (Gilbert, 2007; Swan & Andrews, 2003). Acknowledging the role of shame as individuals embark on their treatment journey would be useful for therapists to gain a deeper understanding of clients. The role of shame needs to be addressed and understood by HCPs at all stages of an individual's journey into services, including referrers who are often the first point of contact for service users. It has been suggested that individuals who are shame-prone may be vulnerable to psychological and interpersonal difficulties (Tangney, Burckhardt & Wagner, 1995; Leither & Baumeister, 1998). This is particularly important to consider and for all HCPs to be aware of given that one of the central expressions of shame is silence; therefore in addition to the ED, shame would be useful to address (Skardevud, 2007). The experience of shame can make an individual feel vulnerable to being rejected, therefore the notion of silence and keeping difficulties that are perceived as shameful i.e. binge eating a secret can serve as a psychological defence for an individual (Gilbert, 1998).

Compassion Focused Therapy (CFT) has been specifically developed to address shame and self-criticism by facilitating self-compassion (Goss, 2010). This research found experiences of shame and lack of self-compassion in individuals experiencing BED, which provides support for the use of interventions that have a focus on self-compassion with this client group. The development of self-compassion has been found to alleviate psychological distress across a range of mental health difficulties (Hoffmann, Grossman, & Hinton, 2011) and CFT has recently been uniquely adapted for EDs in order to address the role of shame and self-criticism (Goss & Allan, 2014).

It has been documented that individuals are unlikely to seek treatment directly for an ED. Mond, Myers, Crosby, Hay, and Mitchell (2010) reported that over 80% of individuals had sought support for general psychological distress rather than EDs, which was attributed

to feeling uncomfortable discussing eating. This was the experience for many participants in this study, who described seeking help for weight increase or general psychological distress, including depressive symptoms. In addition to the interpersonal attributes, research participants reported that they valued being asked about their eating patterns during disclosure, highlighting an important opportunity for clinicians to ask questions about eating and to assess for BED. Previous research has supported this finding that individuals would have welcomed direct questions about eating (Evans et al., 2011).

Given that BED has only been recognised as a formal diagnosis since May 2013 (APA, 2013), this may account for the lack of awareness by HCPs and contribute to delays in identification both by individuals and professionals. The results suggested that there were often difficulties in professionals differentiating between BN, BED and obesity. This is consistent with research, which has found that 33% of primary care physicians in the US pro-actively screened for ED in all patients and 68% in obese patients; however 27% did not recognise BED symptoms, despite it being recognised as a distinct ED in 2013 (Supina et al., 2016). This suggests a need to educate physicians about the specific criteria for BED. As found within this study often the first point of contact for individuals is within primary care services, therefore it is important to consider HCP and GP's knowledge and understanding of BED within these contexts. Such lack of awareness and training may result in a lack of sensitivity during discussion about weight concerns and obesity (Brandsma, 2005; Ebner & Latner, 2013). If training were to be improved, as a result there may be reduced delays in the appropriate identification and treatment for BED (Herman et al., 2014). In line with guidance advocated by the British Psychological Society (2007) clinical psychologists are in a position to provide such training and consultation to HCPs and GPs within primary care training. In particular beginning to introduce and facilitate psychological thinking when HCPs are engaging and integrating with



individuals who may be unaware or in denial about their eating difficulties, and to increase the awareness and detection of BED within primary care services. Denial may serve as an important protective factor in individuals' low self esteem, therefore as an individual begins to acknowledge their illness, acknowledgement of the stages of change and sufficient support has found to be helpful in facilitating this process (Vitousek, Watson & Wilson, 1998). More recently, Vandereycken and Hembreeck (2008) suggested that a balance of confrontation within the context of support and understanding is crucial within the process of problem recognition.

The majority of participants in this study reported that before accessing specialist treatment they had received weight loss advice or intervention from HCPs. This is consistent with Hart et al. (2011) who suggested that individuals commonly receive medical treatment for weight loss rather than mental health care for EDs. Weight loss is not an indicated treatment for BED (Vocks, et al., 2010) therefore this suggests that there is a group of individuals who are not receiving optimal treatment despite having contact with health services. Given this identified need for an increased awareness in both professionals and individuals, continued qualitative research is integral in order to gain a rich and detailed understanding of individuals' experiences in this under-researched and recognised ED.

### **Methodological Considerations, Strengths and Limitations**

IPA was chosen due to the exploratory nature of the research question and the focus on individuals' experiences and a specific phenomenon. Yardley's (2000) criteria for assessing quality were used; each criteria of the quality assessment will be discussed:

**Sensitivity to context.** Existing literature was considered during the development and write up of the research and SU consultation was sought. Care was taken to ensure that rapport was developed, empathy shown and potential power imbalances were considered. Sensitivity to context was maintained throughout analysis

by ensuring that a variety of verbatim extracts were included, giving participants a voice. Acknowledgement of the researcher's experience increased transparency and allows the reader to trace the analysis (Brocki & Wearden, 2006).

**Commitment and rigour.** The sample was purposively selected and homogenous, which ensured that both convergence and divergence could be considered. Smith et al. (2009) recommend the use of divergence and convergence both within and across participants when using IPA as a methodology.

**Transparency and coherence.** This was achieved through the detailed description of the participant selection, interview schedule development, interview process and each stage of the analysis (see Appendix N – R).

**Impact and importance.** Clinical implications and directions for future research have been discussed. In addition, this research has been presented as a poster at the International Eating Disorder Conference, 2016 (Appendix T) and will be presented locally. The findings will be also be presented to local commissioners to increase awareness of BED.

In line with IPA methodology the sample was homogenous: all participants were female; had a diagnosis of BED; and were accessing a specialist ED service. All women had therefore experienced the phenomenon of interest; '*treatment seeking for BED*.' In 2005, Reid, Flowers and Larkin noted that in IPA "less is [described as] more" (p. 756), therefore the sample size allowed for the in-depth examination of transcripts and adhering to IPA's idiographic nature. There was variation in the time since participants had received their diagnosis; this ranged between one week and 10 years, therefore it was not possible to determine whether this produced any differences. Further research is warranted to explore the impact of the BED diagnosis over time.

SU consultation in the development of the research design and interview schedule was a key strength in not only adhering to best practice but also ensuring that the research was meaningful. Future research may benefit from continuing to utilise SU involvement in the development of study design, as this is not something commonly noted within the ED literature.

There are a number of limitations to the research; participants were actively receiving treatment from the ED service where recruitment was carried out, therefore this could have caused a positive bias on participants' experiences of contact with the service. This ethical dilemma was taken into account during data collection and the researcher made clear that their position was independent of the ED team and that participants' transcripts would remain anonymous, this could have impacted on how and what was shared. Whilst credibility checks were carried out, participant validation was not possible due to the limited time scale of the research; taking the analysis back to the participants to determine whether their accounts were accurately captured would have increased both the quality and credibility.

### **Future Research**

Whilst there was no gender specified within the inclusion and exclusion criteria of this research, only female participants were recruited for this study. It was not possible to determine whether this was because of help seeking behaviours differing between males and females or due to a difference in diagnoses received. The experience of gender both within treatment seeking for BED and the experience of diagnosis are important areas for further research. In particular, as within this study the experience of receiving a diagnosis of BED was considered to be helpful, in addition to psychological formulation; however further exploration into what exactly was helpful about the diagnosis is now warranted. Males are often coined as a '*hard to reach*' client group within the ED research field (Räsänen & Hunt,

2014) therefore it would be important to consider carefully where recruitment would be most successful; for example, specific male online forums.

An important and unique finding was the lack of understanding and awareness of BED in both individuals and professionals and not being able to differentiate this from weight related difficulties (i.e. obesity and BED). This is the first study to have found this within the individuals themselves; however the lack of awareness in professionals is consistent with a recent study, which found that 27% of US physicians did not recognise BED symptoms (Supina et al., 2016). General understanding of BED as a distinct ED was found to be limited, which may result in low rates of screening, however would be useful to replicate this in the UK with NHS clinicians.

### **Conclusion**

This study aimed to explore individuals' experiences of treatment seeking for BED. Eight women with a diagnosis of BED were recruited and IPA was used to analyse the data collected through semi-structured interviews. Four super-ordinate themes were identified: *the self as a barrier*; *the overlooked eating disorder*; *factors contributing to treatment seeking and disclosure*; and *making sense of BED*. These findings are of clinical and theoretical relevance to HCPs who interact with individuals experiencing eating difficulties, both inside and outside of specialist services, and may facilitate psychological treatment seeking and tailored service provision for those individuals.

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**Paper 3: Reflective Paper and Commentary**

**This paper is not intended for publication**

### Reflective Paper and Commentary

The objective of this paper is to provide personal and professional reflections on the process of conducting this research. Due to the reflective nature it will be written using the first person. An extension of the methodological considerations and personal experiences that arose during the completion of Paper 2 will be provided. My personal experience of designing and conducting a research project within a National Health Service (NHS) Eating Disorder (ED) Service will be described. The final aim is to explore the themes and issues that arose throughout and the personal impact that they had.

### Research Design

#### Service User Involvement

The world of qualitative research was a new area of study and the idea of designing and constructing an interview schedule was somewhat overwhelming. Service user (SU) involvement and participation is a professional issue of particular interest and in line with best practice I was keen to ensure that I sought SU involvement from the early stages of the research project (Tait & Lester, 2005). I

met with a SU representative from within an NHS trust who had personal experience of binge eating difficulties, to discuss my ideas and research design. This meeting reinforced the message, which I had so often read about, that there is a huge lack of awareness of binge eating disorder (BED) both inside and outside of health services. This meeting left me feeling inspired and reaffirmed that I was completing a research project that would be meaningful.

### **Recruitment**

I was fortunate to gain both university and NHS ethical approval near the beginning of my second year of training, which meant I had a reasonable period of time for recruitment and data collection. Recruitment started off well and I was able to recruit five participants within the first few months. However, following this initial period of data collection, recruitment appeared to hit a wall and there were no further potential participants identified. This created great feelings of anxiety due to the time pressures on the research project and being aware of the lengthy process of data collection, transcription and analysis. Further Research and Development approval was sought from an additional NHS Trust, and whilst this lessened my anxiety in the first instance it soon became apparent that it was unlikely to yield any further participants. I definitely underestimated the timeframe in which it would take to recruit sufficient numbers for the project; it took seven months to recruit eight participants in total. This period of uncertainty and the knowledge that I did not have control was challenging to tolerate and was managed through supervision and peer support.

The recruitment period allowed me to reflect on the challenges of conducting research within clinical practice and in particular, recruiting from a team that I was not a member of. In particular, recruiting from a service that was going through Management of Change meant that I needed to be mindful of these changes when prompting the team regarding recruitment. The balance of managing my own anxiety and motivation to recruit and not putting unnecessary

pressure on the team was difficult to manage at times. Reflecting on this with my clinical supervisor, it was decided that I should take a step back and allow them to continue to prompt the team. In addition to these management changes being in progress, members of the clinical team also shared with my clinical supervisor some ambivalence towards the research being conducted within the service. Whilst the project was well received when I presented at the multi-disciplinary team meeting, staff consequently shared that they had concerns about individuals feeling pressured to take part. This added increased anxiety for me during a time when recruitment had come to a standstill for a number of months, as I felt I was not being proactive and 'doing something.' With hindsight, I wonder whether staff might have felt cautious of being held under scrutiny by the research; for this reason it was important when meeting with the team that I emphasised that the research was focusing on the treatment seeking experience, not specifically discussing the treatment individuals are receiving. It might have been useful to meet with the clinical staff to allow them to share their concerns and to think about how this could be managed; however due to the external and internal pressures staff were being faced with it was decided that this would not be appropriate.

### **Personal Reflections**

#### **Counter Transference**

Due to five participants being interviewed within a short time frame this meant that transcription was completed in an intense block. Following advice from both supervisors and peers I was determined to keep on top of transcription, which meant that I completed these initial interview transcripts over three consecutive days. I was struck by how immersing myself into the data and 're-entering the participants' world' brought food, shape and weight to the forefront of my mind (Smith, Flowers, & Larkin, 2009). I was aware throughout transcription that the dialogue that was both being listened to and transcribed was focused on food, which left me feeling preoccupied with hunger. It was useful

to process and consider my personal responses with my clinical supervisor and to ensure I had adequate time 'away' from the data during both transcription and analysis. It has been documented that working within the field of EDs can commonly influence treatment providers' attitudes and relationships with food and eating (Franko & Rolfe, 1996). More recently, treatment providers for EDs reported that their view of food changed over time and that they became more aware of aspects of their own and other people's appearances (Warren, Crowley, Olivardia, & Schoen, 2009).

### **Conflicting Roles: The Therapist vs. The Researcher**

Throughout the interviews, I often felt torn between my role as a researcher and a therapist. There were times that participants were describing thought patterns, which from a cognitive behavioural perspective could be considered as negative automatic thoughts. In my third year specialist placement I am predominantly working using a cognitive behavioural framework and the focus on these clinical skills and Socratic questioning may have made me particularly attentive to noticing these thought processes and patterns. It was difficult to maintain my role as a researcher and to refrain from challenging these negative thoughts within the interviews. This led me to reflect on whether as a Trainee Clinical Psychologist I was able to truly leave my 'therapy hat' at the door when conducting the research interviews.

I noticed conflict between my role as a researcher and as a therapist, in particular when I experienced a strong emotive response within an interview; this was the case for both positive and negative emotional reactions. A large proportion of the women who took part in the interviews expressed their gratitude at BED being given research attention. Hearing this positive feedback was encouraging and maintained my motivation, which was helpful to hold onto during periods of stress, particularly when managing the demands of my clinical placement, research write up and my personal life.

The emotional reactions I experienced at times mirrored the emotional content that participants expressed, which could be described as countertransference in Psychodynamic Theory (Malan, 1995). There were some participants who expressed a strong sense of worthlessness. In these situations, I can recall experiencing intense feelings of sadness and was drawn towards wanting to use my clinical skills in reflecting back to the participant and recognising their personal strength and resilience. This presented me with a dilemma in which I wanted to alleviate the participant's distress; however I was aware of my role as a researcher and tried to resist engaging in therapeutic conversation. This is a common experience and demonstrated the tension that can arise between the roles of being a scientist and practitioner (Beutler, Williams, Wakefield, & Entwistle, 1995). Supervision was important during these times to think about my role and my own personal reactions to the interviews I was engaging in and also transcribing.

Throughout the entirety of the research I was able to build upon my skills as a researcher and to utilise the skills I was developing whilst being on placement. My clinical skills were fundamental to engaging participants and to ensure they felt comfortable and sufficiently supported to share with me their personal experiences, especially as it was a one off interview there was a relatively short time frame to build up rapport.

### **'Eating Disorders Have No Gender'**

Although there was no gender specified on the inclusion criteria for my research paper, it was notable that there were no male participants. Anecdotally it was apparent through conversations with my clinical supervisor that there were no males actively involved in the service that had a diagnosis of BED during recruitment (May 2015 – January 2016). At the time of writing this reflective paper, there is a current drive to increase awareness of male mental health, including EDs. Notably the Men Get Eating Disorders Too (MGEDT) Charity

have released a documentary called 'Millstone' (MGEDT, 2015), which shares the experiences of nine men who have experienced or are experiencing eating difficulties; the main message from this campaign reads as 'eating disorders have no gender.' In addition to the increased media attention of male EDs there has also been a focus on male mental health. In October 2015, the documentary 'Suicide and Me' featuring Professor Green explored male suicide in an attempt to challenge the stigma often associated with male mental health.

### **Weight, Shape and Society**

Parallel to this positive movement in increasing the public awareness of male mental health, there is an abundance of 'documentaries' that focus on weight. The titles of some of these documentaries include 'Benefits: too fat to work'; 'My Big Benefits Family'; and 'Shut Ins: Britain's Fattest People.' These documentaries are only a few of the programmes that have been aired on British Television in 2015. Society's view of weight, particularly being overweight and/or obese and the shame and stigma associated with this was a powerful theme throughout almost all of the interviews. Having had the privilege of participants sharing with me their personal accounts of treatment seeking for binge eating and hearing that some of the barriers included societal and self-stigma, this left me feeling angry that such documentaries were being aired on television and the perpetuating role this could have on society's view of obesity.

The literature pertaining to gender and weight has been critically examined and it has been highlighted that the very concept of being 'fat' has been feminised (Bordo, 2004). A recent analysis of newspaper representations of EDs in males suggested that men with EDs are represented as atypical of men and that feminine or de-masculinising characteristics are frequently associated (MacLean et al., 2015). I was aware of my role as a white female researcher in my mid-twenties and wondered what impact this might have on the responses participants gave within the interviews. I reflected on the

notion of my role possibly reinforcing the fact that EDs are often associated with female public health and that a large proportion of research is conducted using female participants.

### **The Value of Diagnosis?**

The reliability and clinical utility of diagnostic tools and categories is a controversial topic within the field of psychology. Given the emphasis on social constructionism and the 'critical approach' of the Staffordshire and Keele Doctorate in Clinical Psychology programme, this has been a hot topic of debate throughout teaching. I was struck by the number of participants who shared with me the value of receiving their diagnosis of BED and the personal meaning this held for them. For a number of participants receiving a diagnosis of BED was a validating and critical part of their journey to seeking specialist treatment. This allowed me to reflect on the positive impact such diagnoses can have for individuals, for many this diagnosis meant that they were then eligible and met the necessary criteria in order to access specialist treatment. This highlighted the importance placed upon diagnostic criteria by services. The way in which NHS services are currently set up within mental health reinforces the use of specific diagnoses, as this is frequently a criteria for accessing specialist treatment.

Professionally, my thinking is in line with the recent Division of Clinical Psychology response to the DSM-5 (2013), which advocates formulation over diagnosis. Conducting this research has however allowed me to take into account the usefulness of receiving a diagnosis for some individuals and the importance of exploring this on an individual basis.

Discussion with SUs in the development of the research design and the interview schedule also raised the topic of the language used and it was decided that eating *difficulties* rather than eating *disorder* would be more appropriate. When listening back to transcripts I noticed that I said the words 'binge eating' in a quieter and more



tentative manner in comparison to the rest of the sentence. This could have been a result of wanting to get the wording 'right' and to try and be sensitive to the participant due to my own uncomfortable feelings with the diagnostic label. Transcribing after each interview allowed me to pick up on such nuances and processes, which were rife within each interview. Awareness of this permitted useful discussions within supervision and this allowed me to further reflect on the possible exacerbating impact this could have on the associated stigma with BED. I was therefore able to ensure that I did not collude with this stigma and say the words with confidence.

### **Summary**

Throughout each and every one of the interviews conducted I felt in a privileged position to hear the individual stories and experiences from participants. I was struck by the candid nature of the women and their resilience throughout their journey to seek specialist treatment. I have developed both personally and professionally throughout this research project, specifically within my research skills, and this has reaffirmed to me the importance of supervision and self-reflection within a research role. I have had to tolerate uncertainty and manage being in a position of limited control, particularly during the early stages of the research.

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## Appendix A: Guidelines for Submission to the European Eating Disorders Review

### Submission guidelines for authors



### European Eating Disorders Review

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Edited By: Professor Fernando Fernandez-Aranda

Impact Factor: 2.252

ISI Journal Citation Reports © Ranking: 2013: 34/111 (Psychology Clinical)O

Online ISSN: 1099-0968



### Author GuidelinesL Manuscript Submission

European Eating Disorders Review has now adopted ScholarOne Manuscripts, for online manuscript submission and peer review. The new system brings with it a whole host of benefits including:

- **Manuscript style.** All submissions should be double-spaced and clearly legible.
- The first page should contain the **title** of the paper, full names of all authors, th address where the work was carried out, and the full postal address including telephone, fax number and email to whom correspondence and proofs should be sent.
- **Abstract** of up to 150 words. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. Include up to five **keywords** that describe your paper for indexing purposes.
- **Review articles** should offer a synthesis of current knowledge in a field where rapid or significant progress has been made. The text should ideally not exceed 7000 words, 50 references and 5 figures or tables.
- **Reference style** . The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper.

## Appendix B: DSM-5 Diagnostic Criteria for Anorexia Nervosa, Bulimia Nervosa and Binge Eating Disorder

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### Diagnostic Criteria - Anorexia Nervosa

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- A. Persistent restriction of energy intake leading to significant low body weight (in context of what is minimally expected for age, sex, developmental trajectory and physical health).
- B. Either an intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain (even though significantly low weight)
- C. Disturbance in the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation or persistent lack of recognition of the seriousness of current low body weight.

#### Subtypes:

Restricting type

Binge-eating/purging type

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### Diagnostic Criteria - Bulimia Nervosa

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- A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:
    - Eating, in a discrete period of times (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances.
    - A sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating).
  - B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, fasting or excessive exercise.
  - C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months.
  - D. Self-evaluation is unduly influenced by body shape and weight.
  - E. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.
-

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### Diagnostic Criteria – Binge Eating Disorder

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- A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:
- Eating, in a discrete period of time (e.g., within any 2-hour period) an amount of food that is definitely larger than what most people would eat in a similar period of time under similar circumstances.
  - A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control how much one is eating).
- B. The binge-eating episodes are associated with three (or more):
- Eating much more rapidly than normal.
  - Eating until feeling uncomfortably full.
  - Eating large amounts of food when not physically hungry
  - Eating alone because of feeling embarrassed by how much one is eating.
  - Feeling disgusting with oneself, depressed, or very guilty afterward.
- C. Marked distress regarding binge eating is present.
- D. The binge eating occurs, on average, at least once a week for 3 months.
- E. The binge eating is not associated with the recurrent use of inappropriate compensatory behaviour as in bulimia nervosa and does not occur exclusively during the course of bulimia nervosa or anorexia nervosa.

*Specify if:*

**In partial remission:** After full criteria for binge-eating disorder were previously met, binge eating occurs at an average frequency of less than one episode per week for a sustained period of time.

**In full remission:** After full criteria for binge-eating disorder were previously met, none of the criteria have been met for a sustained period of time.

*Specify current severity:*

The minimum level of severity is based on the frequency of episodes of binge eating (see below). The level of severity may be increased to reflect other symptoms and the degree of functional disability.

**Mild:** 1-3 binge-eating episodes per week.

**Severe:** 8-13 binge-eating episodes per week.

**Extreme:** 14 or more binge-eating episodes per week.

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## Appendix C: Crowe Critical Appraisal Tool (CCAT, 2013)

Appraise research on the merits of the research design used, not against other research designs.

Category Item	Item descriptors [ <input type="checkbox"/> Present; <input type="checkbox"/> Absent; <input type="checkbox"/> Not applicable]	Description [Important information for each item]	Score [0–5]
<b>1. Preliminaries</b>			
Title	1. Includes study aims <input type="checkbox"/> and design <input type="checkbox"/>		
Abstract (assess last)	1. Key information <input type="checkbox"/> 2. Balanced <input type="checkbox"/> and informative <input type="checkbox"/>		
Text (assess last)	1. Sufficient detail others could reproduce <input type="checkbox"/> 2. Clear/concise writing <input type="checkbox"/> , table(s) <input type="checkbox"/> , diagram(s) <input type="checkbox"/> , figure(s) <input type="checkbox"/>		
Preliminaries [/5]			
<b>2. Introduction</b>			
Background	1. Summary of current knowledge <input type="checkbox"/> 2. Specific problem(s) addressed <input type="checkbox"/> and reason(s) for addressing <input type="checkbox"/>		
Objective	1. Primary objective(s), hypothesis(es), or aim(s) <input type="checkbox"/> 2. Secondary question(s) <input type="checkbox"/>		
Is it worth continuing?			Introduction [/5]
<b>3. Design</b>			
Research design	1. Research design(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of research design(s) <input type="checkbox"/>		
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Precise details of the intervention(s)/treatment(s)/exposure(s) <input type="checkbox"/> for each group <input type="checkbox"/> 3. Intervention(s)/treatment(s)/exposure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>		
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) <input type="checkbox"/> 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid <input type="checkbox"/> and reliable <input type="checkbox"/>		
Bias, etc	1. Potential bias <input type="checkbox"/> , confounding variables <input type="checkbox"/> , effect modifiers <input type="checkbox"/> , interactions <input type="checkbox"/> 2. Sequence generation <input type="checkbox"/> , group allocation <input type="checkbox"/> , group balance <input type="checkbox"/> , and by whom <input type="checkbox"/> 3. Equivalent treatment of participants/cases/groups <input type="checkbox"/>		
Is it worth continuing?			Design [/5]
<b>4. Sampling</b>			
Sampling method	1. Sampling method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of sampling method <input type="checkbox"/>		
Sample size	1. Sample size <input type="checkbox"/> , how chosen <input type="checkbox"/> , and why <input type="checkbox"/> 2. Suitability of sample size <input type="checkbox"/>		
Sampling protocol	1. Target/actual/sample population(s): description <input type="checkbox"/> and suitability <input type="checkbox"/> 2. Participants/cases/groups: inclusion <input type="checkbox"/> and exclusion <input type="checkbox"/> criteria 3. Recruitment of participants/cases/groups <input type="checkbox"/>		
Is it worth continuing?			Sampling [/5]
<b>5. Data collection</b>			
Collection method	1. Collection method(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Suitability of collection method(s) <input type="checkbox"/>		
Collection protocol	1. Include date(s) <input type="checkbox"/> , location(s) <input type="checkbox"/> , setting(s) <input type="checkbox"/> , personnel <input type="checkbox"/> , materials <input type="checkbox"/> , processes <input type="checkbox"/> 2. Method(s) to ensure/enhance quality of measurement/instrumentation <input type="checkbox"/> 3. Manage non-participation <input type="checkbox"/> , withdrawal <input type="checkbox"/> , incomplete/lost data <input type="checkbox"/>		
Is it worth continuing?			Data collection [/5]
<b>6. Ethical matters</b>			
Participant ethics	1. Informed consent <input type="checkbox"/> , equity <input type="checkbox"/> 2. Privacy <input type="checkbox"/> , confidentiality/anonymity <input type="checkbox"/>		
Researcher ethics	1. Ethical approval <input type="checkbox"/> , funding <input type="checkbox"/> , conflict(s) of interest <input type="checkbox"/> 2. Subjectivities <input type="checkbox"/> , relationship(s) with participants/cases <input type="checkbox"/>		
Is it worth continuing?			Ethical matters [/5]
<b>7. Results</b>			
Analysis, Integration, Interpretation method	1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen <input type="checkbox"/> and why <input type="checkbox"/> 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen <input type="checkbox"/> and why <input type="checkbox"/> 3. Suitability of analysis/integration/interpretation method(s) <input type="checkbox"/>		
Essential analysis	1. Flow of participants/cases/groups through each stage of research <input type="checkbox"/> 2. Demographic and other characteristics of participants/cases/groups <input type="checkbox"/> 3. Analyse raw data <input type="checkbox"/> , response rate <input type="checkbox"/> , non-participation/withdrawal/incomplete/lost data <input type="checkbox"/>		
Outcome, Output, Predictor analysis	1. Summary of results <input type="checkbox"/> and precision <input type="checkbox"/> for each outcome/output/predictor/measure 2. Consideration of benefits/harms <input type="checkbox"/> , unexpected results <input type="checkbox"/> , problems/failures <input type="checkbox"/> 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) <input type="checkbox"/>		
Results [/5]			
<b>8. Discussion</b>			
Interpretation	1. Interpretation of results in the context of current evidence <input type="checkbox"/> and objectives <input type="checkbox"/> 2. Draw inferences consistent with the strength of the data <input type="checkbox"/> 3. Consideration of alternative explanations for observed results <input type="checkbox"/> 4. Account for bias <input type="checkbox"/> , confounding/effect modifiers/interactions/imprecision <input type="checkbox"/>		
Generalisation	1. Consideration of overall practical usefulness of the study <input type="checkbox"/> 2. Description of generalisability (external validity) of the study <input type="checkbox"/>		
Concluding remarks	1. Highlight study's particular strengths <input type="checkbox"/> 2. Suggest steps that may improve future results (e.g. limitations) <input type="checkbox"/> 3. Suggest further studies <input type="checkbox"/>		
Discussion [/5]			
<b>9. Total</b>			
Total score	1. Add all scores for categories 1–8		
Total [/40]			

### Appendix D: CASP Checklist Scores

1. Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y
2. Was the research design appropriate to address the aims of the research?	P	Y	Y	Y	Y	Y
3. Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y
4. Was the data collected in a way that addressed the research issue?	P	Y	Y	Y	Y	Y
5. Has the relationship between the researcher and participants been adequately considered?	P	N	N	N	N	N
6. Have ethical issues been taken into consideration?	Y	Y	Y	Y	Y	Y
7. Was the data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	P
8. Is there a clear statement of the findings?	Y	Y	Y	Y	Y	P
9. How valuable is the research?	Y	Y	Y	Y	Y	P

#### Key:

Y	Yes
P	Partially Met
N	No



### Appendix E: Crowe Critical Appraisal Tool Scores

Category Item	Griffiths et al. (2015)	Gilbert et al. (2012)
1. Preliminaries ( /5)	4	4
2. Introduction ( /5)	5	5
3. Design ( /5)	4	3
4. Sampling ( /5)	4	3
5. Data collection ( /5)	4	4
6. Ethical matters ( /5)	2	3
7. Results ( /5)	5	4
8. Discussion ( /5)	5	5
9. Total ( /40)	33	31
<b>Total (%)</b>	<b>83%</b>	<b>78%</b>

## Appendix F: Eating Disorder Screening Tools

Eating Disorder Screening Tool	Description of the Screening Tool
Eating Disorder Examination (EDE: Fairburn & Cooper, 1993)	The EDE is a semi-structured interview, which is conducted by a trained clinician and is used to provide information to aid the diagnosis of an ED. It provides a measure of the range and severity of ED features. It is widely recognised as the gold standard screening measure of ED symptoms. The current version is the EDE 17.0D, which has been adapted in line with the DSM-5 ED diagnostic criteria (APA, 2013). The EDE contains four subscales: restraint; eating concern shape concern; and weight concern. Behaviours relating to these subscales are measured over a 28-day period and scored from 0-6, with zero indicating no days and six everyday. This provides information regarding the frequency of key behavioural features of EDs and the number of days these occur. Subscale scores are derived in addition to an overall 'global' score.
Eating Disorder Examination Questionnaire (EDE-Q: Fairburn & Beglin, 1994; 2008)	Due to the extensive training and the length of time needed to complete the EDE, the EDE-Q was developed as an efficient and cost-effective alternative. The EDE-Q is a 41 item self-report version of the full EDE interview and it has been normed for both adolescents and adults. Questions are concerned with the past 28 days and are scored from 0-6, with zero indicating no days and six everyday. It has the same four subscales as the EDE and also generates an overall 'global' score.

## Appendix G: Qualitative Health Research Submission Guidelines



*Qualitative Health Research (QHR)* is an international, interdisciplinary, refereed journal for the enhancement of health care and furthering the development and understanding of qualitative research methods in health care settings. We welcome manuscripts in the following areas: the description and analysis of the illness experience, health and health-seeking behaviors, the experiences of caregivers, the sociocultural organization of health care, health care policy, and related topics. We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

### **Author Guidelines for submission:**

- No word limit
- APA referencing style
- Word document
- Title, keywords and abstract to accompany article
- Consent given by all authors for submission.

**Appendix H: Independent Peer Review Ethical Approval:  
Staffordshire University**



**INDEPENDENT PEER REVIEW APPROVAL FEEDBACK**

<b>Researcher Name</b>	Charlotte Evans
<b>Title of Study</b>	The experience of treatment seeking for Binge Eating Disorder: an Interpretative Phenomenological Analysis.
<b>Award Pathway</b>	
<b>Status of approval:</b>	<b>Approved</b>

Thank you for forwarding the amendments requested by the Independent Peer Review Panel (IPR)

**Action now needed:**

You must now apply to the Local Research Ethics Committee (which serves the Trust within which you intend to complete your study) for approval to conduct your study. You must not commence the study without this second approval. To seek approval you will need to complete the application form for the committee and forward copies of your proposal.

Please forward a copy of the letter you receive from the L.R.E.C. to Andrea Boardman at the Science Centre as soon as possible after you have received approval. Once you have received L.R.E.C. approval you can commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

It is now possible to begin writing your dissertation and you may wish to consult with your supervisor on this matter.

**Signed:** Dr E Boath

**Date:** 12<sup>th</sup> November 2014

Chair of the Faculty of Health Sciences IPR Panel

**Appendix I: Greater Manchester West Research Ethics Committee**  
**NHS Ethical Approval**



**NRES Committee North West - Greater Manchester West**

Barlow House  
 3rd Floor  
 4 Minshull Street  
 Manchester  
 M1 3DZ

20 January 2015

Miss Charlotte Evans  
 Trainee Clinical Psychologist  
 South Staffordshire and Shropshire Healthcare NHS Foundation Trust  
 Staffordshire and Keele DClinPsy  
 R101, Faculty of Health Sciences, Staffordshire University, Science Centre  
 Leek Road, Stoke on Trent  
 ST4 2DF

Dear Miss Evans

**Study title:** The experience of binge eating and treatment seeking for Binge Eating Disorder: An Interpretative Phenomenological Approach.  
**REC reference:** 15/NW/0012  
**IRAS project ID:** 157823

Thank you for your email of 20 January 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 15 January 2015.

**Documents received**

The documents received were as follows:

Document	Version	Date
Participant consent form [Informed Consent Form]	2.0	20 January 2015
Participant information sheet (PIS) [Participant Information Sheet]	2.0	20 January 2015

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor insurance or indemnity ]	1.1	20 November 2014
Interview schedules or topic guides for participants [Interview topic guide]	1.1	19 November 2014
IRAS Checklist XML [Checklist_09122014]		09 December 2014
Letter from sponsor [Letter from sponsor (university)]	1.1	19 November 2014
Letters of invitation to participant		
Other [Email Clarification]		15 December 2014

Participant consent form [Informed Consent Form]	2.0	20 January 2015
Participant information sheet (PIS) [Participant Information Sheet]	2.0	20 January 2015
REC Application Form [REC_Form_09122014]		09 December 2014
Referee's report or other scientific critique report [Referee's report or other scientific report]	1.1	20 November 2014
Referee's report or other scientific critique report		16 December 2008
Research protocol or project proposal	1.1	14 December 2014
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator]	1.1	28 November 2014
Summary CV for supervisor (student research) [Summary CV for supervisor]	1.1	20 November 2014
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Flowchart of the protocol]	1.1	19 November 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**15/NW/0012**

**Please quote this number on all correspondence**

Yours sincerely



**Miss Katie Southeard**  
**REC Assistant**

E-mail: [nrescommittee.northwest-gmwest@nhs.net](mailto:nrescommittee.northwest-gmwest@nhs.net)

Copy to: *Dr Helena Priest*  
*Ms Audrey Bright, South Staffordshire and Shropshire Healthcare NHS*  
*Foundation Trust*

**Appendix J: Research and Development approval: South  
Staffordshire and Shropshire Healthcare NHS Foundation Trust**

South Staffordshire and Shropshire Healthcare   
NHS Foundation Trust

*A Keele University Teaching Trust*

Our Ref: AB/R319

R&D Department

Block 7

Date: 24 January 2015

St George's Hospital

Corporation Street

STAFFORD ST16 3AG

Telephone: 01785 783170

Ms Charlotte Evans



Trainee Clinical Psychologist  
 Room 101, Faculty of Health Sciences  
 Staffordshire University  
 Science Centre, Leek Road  
 Stoke on Trent ST4 2DF

Dear Charlotte

**Study title: The experience of treatment seeking for binge eating disorder**

We have considered your application for access to patients and staff from within this Trust in connection with the above study.

On behalf of the Trust and the Responsible Care Professionals within the Psychology Directorate have now satisfied themselves that the requirements for Research Governance, both Nationally and Locally, have been met and are happy to give approval for this study to take place in the Trust, with the following provisos:

- That all researchers coming into the Trust have been issued with either a letter of access or honorary contract by ourselves
- That you conform to the requirements laid out in the letters from the REC dated 20 January 2015, which prohibits any changes to the agreed protocol
- That you keep the Trust informed about the progress of the project at 6 monthly intervals
- If at any time details relating to the research project or researcher change, the R&D department must be informed.

Your research has been entered into the Trust database and will appear on the Trust website.

As part of the Research Governance framework it is important that the Trust are notified as to the outcome of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. You will be asked to provide a copy of the final report and receive an invitation to present final feedback via our research seminar series. To aid dissemination of findings, copies of final reports are placed on our Trust Website. To this end, please contact me towards the completion of the project to discuss the dissemination of findings across the Trust and a possible implementation plan.

If I can help in any other way please do not hesitate to contact me.

Yours sincerely

Ruth Lambley-Burke

Head of R&D

Cc Dr Rachel Lucas, Director of Psychological Services, Trust HQ, Stafford

## Appendix K: Letter of invitation and Participant Information Sheet



South Staffordshire and Shropshire Healthcare   
 NHS Foundation Trust  
 A Keele University Teaching Trust

### **Letter of invitation for participants**

**Study Title:** The experience of treatment seeking for Binge Eating Disorder: an Interpretative Phenomenological Analysis.

Dear Sir/Madam

I am completing a research study as part of my Doctorate in Clinical Psychology at Staffordshire and Keele Universities. I would like to invite you to participate in this study, which is investigating the experience of binge eating and treatment seeking for individuals with a diagnosis of Binge Eating Disorder.

It is your decision whether you decide to take part. If you are interested in participating, please provide your group facilitator with your preferred

method of contact, using the slip below. I will then send you Participant Information, Consent Form and an interview date/time.

If you decide that you do not want to take part, this will not affect your treatment now or in the future.

Should you require any further information please do not hesitate to contact me:

Charlotte Evans: [e030777c@student.staffs.ac.uk](mailto:e030777c@student.staffs.ac.uk)

Many thanks for your consideration to participate in this study. It is much appreciated.

Kind regards  
Charlotte Evans  
**Researcher**

Name: .....

Preferred method of contact (telephone number/ email address / postal address)  
.....

I agree for Charlotte Evans (Researcher) to contact me using the above contact details with further information about this study.

Signed: .....

Date: .....



South Staffordshire and Shropshire Healthcare   
NHS Foundation Trust  
A Keele University Teaching Trust

### **Participant Information Sheet**

**Study Title:** The experience of treatment seeking for Binge Eating Disorder: an Interpretative Phenomenological Analysis.

You are invited to take part in this study, as I understand that you have attended or are currently attending the Binge Eating group or have recently been seen for an assessment.

My name is Charlotte Evans and I am completing my Doctorate in Clinical Psychology at Staffordshire and Keele Universities. Before you decide whether you would like to take part in this study, it is important that you understand why it is being conducted and what will be required. If you

decide not to take part, this will not have any affect on your treatment now or in the future.

*Should you require any further information or you have any questions please do not hesitate to contact me or my supervisor using the contact details below.*

### ***What is the study about?***

This study is exploring individuals' experiences of treatment seeking for Binge Eating Disorder.

### ***What will it involve?***

If you decide that you would like to take part in this study, you will be required to sign a Consent Form. You will then be invited to take part in an interview at the clinic, at a date and a time that is convenient. This interview will be with Charlotte Evans (Researcher) and will be recorded using a Dictaphone. The interview may take from 20 minutes up to an hour to complete and will be asking you about your experiences of binge eating and seeking treatment.

### ***Confidentiality***

All data will remain anonymous, which means that no identifying information (e.g. name) will be included in any draft of this study. The interviews will be transcribed and kept in a locked, confidential place. All data will be stored on a password protected data stick and will be transcribed using an encrypted NHS laptop. Interviews will be deleted from the Dictaphone following transfer to the password protected data stick. This will be done directly after the interview has been completed.

The transcripts from interviews will not be used for any other research. Parts of the transcripts may be shared with my supervisors. The transcripts will not be shared with the clinical team. The data may need to be made available to Regulatory Authorities to for audit; however the data used will be anonymous and contain no personal information.

Once data analysis is complete the anonymised data it will be kept in a secured filing cabinet for 5 years at Staffordshire University and destroyed thereafter. No personal information or identifying material will be stored.

It must be noted that if there are any concerns regarding risk, which arise as a result of the interview, then these will be shared with the Eating Disorder Team and/or your care coordinator. This includes potential risk issues for you or for others.

### ***Deciding whether to take part***

It is entirely up to you if you wish to participate in this study. If you would like to take part you will be required to complete a consent form. You are

able to withdraw your data up to 2 weeks after the interview. If you decide you do not want to take part, this will not affect your treatment now or in the future.

There are no direct benefits for you taking part in this study however you will help to make a research contribution and possible service developments. There are no identified risks for you taking part, however if you experience difficulties or have concerns following the interview, please contact your care coordinator or Dr. Kierron Worley (Clinical Psychologist).

**Dr. Kierron Worley:** 01785 783 120

Below are the contact details for the B-eat Helpline, which is open to anyone who needs support related to an eating disorder:

**B-eat Helpline :** 0845 634 1414

**Email:** [help@b-eat.co.uk](mailto:help@b-eat.co.uk)

Although the interviews will be kept confidential, if there any risks highlighted, this will need to be broken and the information communicated to the Eating Disorder Service Team.

If you have a concern about any aspect of this study, you should speak to the researchers on the contact details below who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this using the NHS Complaints Procedure. Details can be obtained from the Patient Advice and Liaison Service (PALS) 01785 783 028 (10am to 4pm Monday – Friday) or [pals@sssft.nhs.uk](mailto:pals@sssft.nhs.uk)

### ***How can I find out the results?***

The full write up will be completed by April 2016 and will be available to read at Staffordshire University Library. It may also be published in a psychological journal, which will be used to inform future clinical practice. You may request the results and be provided with a summary. If you would like this information, please provide an email contact below:

**E-mail:** .....

### ***Researcher Contact Details***

If you would like further information, please do not hesitate to contact me: [e030777c@student.staffs.ac.uk](mailto:e030777c@student.staffs.ac.uk)

You can also contact my research supervisor Dr. Helena Priest at:

Staffordshire and Keele Clinical Doctorate Training  
Faculty of Sciences, Staffordshire University  
Leek Road, Stoke-on-Trent, ST4 2DF

*Thank you for taking the time to read this information sheet.*

## Appendix L: Informed Consent



South Staffordshire and Shropshire Healthcare   
 NHS Foundation Trust  
 A Keele University Teaching Trust

### Informed Consent

**Study Title:** The experience of treatment seeking for Binge Eating Disorder: an Interpretative Phenomenological Analysis.

**Researcher:** Charlotte Evans      **Email:** [e030777c@student.staffs.ac.uk](mailto:e030777c@student.staffs.ac.uk)

Please tick if you consent:

- I have read and understood the information sheet. ☐
- I understand that I may ask further questions at any time and my questions so far have been answered to my satisfaction. ☐

- I understand that taking part in this study is optional and I may withdraw my data up to 2 weeks after the interview. ☐
- I am aware of the potential benefits and risks to participating. ☐
- I understand that my participation is confidential, however if there are concerns regarding risk to myself or to others then this information will be shared with the Eating Disorder Team. ☐
- I understand that my interview will be audio recorded and transcribed by the researcher. ☐
- I understand that relevant sections of my medical notes and data collected during this study, may be looked at by individuals from Staffordshire University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records. ☐
- I understand that my direct quotations (anonymised) may be used in future publication(s). ☐

**I ..... (Full Name) consent to take part in this study.**

**Signature:** ..... **Date:** .....

**Researcher:** Charlotte Evans

**Signature:** ..... **Date:** .....

#### **Appendix M: B-eat ED Website Advertisement**


 Enter your search query 

Helpline 0845 634 1414 Youthline 0845 634 7650

[About Eating Disorders](#) [Support & Services](#) [For Professionals](#) [Support Us](#) [Volunteering](#) [Research](#) [About Beat](#)

[Participate in Research](#)

[Summary of Completed Research](#)

[Work with us as a Researcher](#)

[Beat's Lottery Funded Research](#)

## Treatment seeking in Binge Eating Disorder

Author	Charlotte Evans	Contact Email: <a href="mailto:c.m.evans@hotmail.co.uk">c.m.evans@hotmail.co.uk</a>
Affiliation	University of Staffordshire/Keele University	
Contact Name:	Charlotte Evans	

Charlotte Evans, Trainee Clinical Psychologist, Staffordshire and Keele Universities.

### Purpose of Study:

The aim of my doctoral research is to explore the experiences of binge eating disorder and the experience of seeking treatment. In comparison to the other eating disorders there is limited research into binge eating disorder, and in particular exploring individual's experiences. This research will use interviews and individuals will be asked to talk about their experiences of binge eating and treatment seeking.

### Development of interview topic guide:

I am really keen for individuals who have lived experience of binge eating to be involved in the development of the interview topic guide. Through consultation and feedback on this interview topic guide, I hope that it will be meaningful for the participants in the research.

If you are interesting in providing consultation or feedback on the interview topic guide, please contact me at [e030777c@student.staffs.ac.uk](mailto:e030777c@student.staffs.ac.uk).

## Appendix N: Examples of Line-by-line Coding



491.	last week, but I don't feel like I am able to talk	unable to discuss with people without being flippant.	
492.	about it with people without being flippant.	struggle discuss & others	
493.	What sense do you make of that, that you need	- embarrassed? - shame? - not feel persons? - self blame?	Assumed - ED = thin. (anorexia)
494.	to be flippant?	assumption have ED - thin.	Stereotype of eating disorder.
495.	Is it that assumption that if you have an eating	anorexia	Compare to other ED?
496.	disorder, you're thin, that you're anorexia? I	I don't know - lack of clarity & feel?	
497.	don't know. [pause]. I don't know. [pause] But	going back to work.	
498.	I felt like umm, like going into work, and its all	People asking how it was.	
499.	like how did you get on how did you get on?	Remember to be sick. secretly.	
500.	You know, so you have got to remember to be	Make a joke.	External (persona) flippant vs.
501.	sick or, you know, which I would make joke,	Flippant. Externally.	Internal (emotion) dissonance.
502.	but I would make flippant joke anyway	struggle with share & others	
503.	externally anyway. But no I really struggle with		
504.	and that's I actually think, pardon the pun are		

505.	you going to have the surgery naah I have an	Dismissive. Not taken seriously.	Not allow self to take diagnosis seriously.
506.	eating disorder type thing. I was talking to a	eating disorder type thing.	Others not understand/accept.
507.	friend and she was like well, the whole majority	talking to friend.	Struggle to accept diagnosis of BED.
508.	of the population are obese, so has everyone	Majority population obese	
509.	got an eating disorder then? [pause] and I cant,	everyone have ED.	
510.	I was like, struggling with that like I don't	unsure. don't know.	Population obese - all ED? Rejecting of ED?
511.	know? So, [pause]	uncertain. unanswered questions.	
512.	How did that feel?		
513.	Umm... that I was being a drama queen. That I	Drama queen.	Not deserving. Label excuse.
514.	am joining the bandwagon of lazy people, using	Join bandwagon of lazy people	
515.	the excuse as a label that was how it felt.	label as an excuse.	Self-stereotype
516.	Was that a recent conversation?	Strong words - no hesitation.	
517.	Last week. Friday, yeah yeah Friday. Hmmm	Clear on these points.	
518.	[pause] so it isn't something that I can, umm	Last week, Friday.	

14	years for me to get to that point. He weighed me	2-3 yrs to get to that point.	Process to get help
15	and told me that I was a normal weight and that	W. weighed - 'normal' weight	Critical point.
16	everything was fine. So, after that I just thought I	told him. <i>Dismissed by Dr?</i>	Dismissed.
17	had got nowhere to go really on this, umm, and it	Nowhere to go. Not gone away.	Nowhere to turn - feel alone? Isolated?
18	it's it's never gone away. Umm, sometimes I'd say I	Constant in life.	
19	could probably binge on a good week twice a	twice a week - 'good week'	
20	week and then a bad week could be probably four	'bad week' 4-5 times.	good vs. bad (extremes)
21	or five times a week. Umm, I know when I was	<i>Specimens important. uncertain, pause.</i>	Critical of self.
22	pregnant, not sure if it was with [name] ... [pause]	Pregnant.	
23	I think it was [name] I was still going to like	going to weight watchers	Dieting.
24	weight watchers class umm but I know I was	<i>Critical event - pregnancy.</i>	
25	bingeing every other day, every <i>Repeated</i> that's right every	Binging every other day	
26	<i>clearly</i> other day. Because I remember being concerned	(discussed about unborn baby)	feeling responsible for child.
27	about what was going to do to her. When I was	<i>Lack of self concern - concern for others.</i>	

70	to see you like this, what do you mean by that?		
71	Well, fat really <i>laughs</i> because I think because I	Fat.	Want to hide (external physical appearance).
72	looked different before, I think especially because, I	Looked different before.	
73	think its going from a low weight to a high weight it	move low → high weight.	Transition low → high weight
74	is such a significant difference that like, I did know	significant difference felt.	AN → BED. change physically
75	that I wasn't comfortable at the low weight but I	Not comfortable low but	
76	still went out whereas now I, I don't want to go out	went out - now don't	Emotions of weight
77	and I didn't like, for my 18 <sup>th</sup> I didn't even do	Not do anything 18 <sup>th</sup> birthday	Weight + binge = powerful.
78	anything <i>laughs</i> so. <i>Nervous laughter</i> <i>uncomfortable?</i>	Binge (w/ weight prevents from doing things socially - want to hide, people not see 'fat'. Shame?)	feel embarrassed?
79	What do you think is that difference for you		hide external appearance.
80	between the low and high weight?	<i>Hesitation - uncertain how to articulate feelings / experience</i>	Fear judgement of others?
81	Umm, well, I know it's a lot of people have, I would	<i>explaining self?</i>	
82	<i>never ever judge anyone</i> I don't think, but for me	<i>Justifying self?</i>	
83	myself ummm I don't know, I don't want to be umm	<i>asked what question was.</i>	

## Appendix O: Emergent Themes for Participant Four in Chronological Order

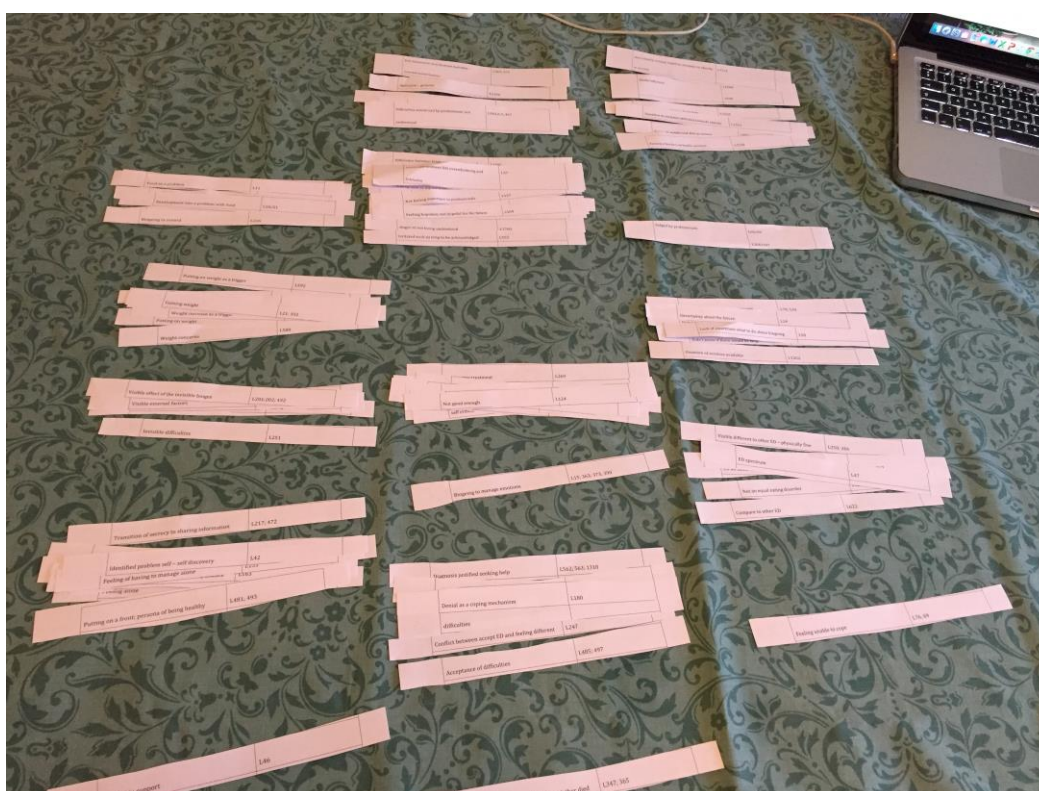
Theme	Line
Understanding of the cause	L4/5
Secretive	L9
Loss of control	L16
Hide physical evidence of the binge	L19;20
Embarrassed; ashamed of self	L25; 41
Use as emotional coping strategy	LL32
Secrecy was stressful	L25
No choice – compulsion to binge	L39
Cut off - disconnected from the binge	L45
Do not feel normal	L48
“False self” Persona to other people that eat healthily. Putting on a front to other people.	L51; 59; 82
Ashamed of the types of foods	L54
Secrecy of binges - alone	L69
Feel failure – cannot stop	L77
No choice or control	L76
Denial to others and self	L86
Physical side effects of binge eating	L94
Self blame	L115
Medication prescribed for anxiety	L118
Did not want diagnosis	L129
Stigma associated with diagnosis	L132
Critical point reached then went to get help – acceptance	L135
Self initiated disclosure to GP	L141
Anxious about admitting to GP	L146
Relief	L153
Transition to more accepting of possible diagnosis	L155; 188
Diagnosis identified as needed to get help	L155
Worried would be seen as not capable of job / not coping	L174
Fear of discrimination within the workplace	L170
Avoidance of thinking about bingeing	L181
Prioritised job	L178
Diagnosis would make it real – denial	L183
Secrecy	L184
Not admit difficulties to others or self	L191

Theme	Line
Medication did not reduce binges	L199
Critical point – had enough; impact of binges of self	L205
Initial assumption by others = bulimia	L212
Lack of understanding and awareness	L220
Explaining self and behaviours	L221
Professional was dismissive – not taken seriously	L230
Interpersonal qualities important to feel safe to disclose	L225
Numerous professionals involved	L236
Frustrated at the system to access help	L241
Fearful there would be no help – lack of awareness of available treatments	L245
Feared professionals would not understand	L244; 249
Anxious but put at ease	L254
Expectation not met – relief when specialist service referral.	L260; 263
Perceived difference between counselling and specialist service	L257
Not expected to be taken seriously as did not take self seriously	L270
Self blame “I didn’t need to do it”	L274
Self discovery and understanding – researched symptom of BED	L286
Lack of understanding from others	L292
Justify self – explain self	L305
Difficult to talk about weight	L320
Optimism	L324
Worthy of treatment	L327
Grateful had been believed and taken seriously	L225; 337
Weight off shoulders	L349
Hopeful for the future	L347
Inclusive did not feel alone – supportive	L358
Process of acceptance of difficulties and help	L363
Learning self compassion	L366
Permission to accept that was not a choice	L368
Validating of difficulties	L372
Questions directly related to eating was normalising	L374
Emotional aspects explored – facilitated understanding	L379
Understand the bigger picture	L382
Felt desperate - motivated to change	L389
Taken seriously and understood	L399
Linking thoughts feelings and behaviours – formulation of current difficulties	L400
Believed it was not my choice	L405
Uncertain what to do about BED? Lack of awareness of treatment options	L417

Theme	Line
External self and behaviours – judged negatively by others	L420
Cutting off from emotions	L422
not understood as a psychological by others	L428
Not well recognised	L434
Media representations of obesity	L430
Not understood	L437
Not understood or recognised by individuals suffering	L442
Self-researched difficulties	L445
No publicity for BED	L453
Value of close people for support	L458
An isolating experience	L460
Validation from seeing diagnosis	L470
Diagnosis on NHS website – optimistic for help	L471
Avoid diagnosis on records –stigma?	L483
Importance of specialist referral and help	L496
Externally judge self-based on shape and weight	L548
Social comparison (weight and shape)	L550
Impact of weight on sense of self and identity	L547
Eating emotional coping mechanism	L589
Understanding why bingeing happens important	L637



## Appendix P: Development of Connections between Emergent Themes for Participant Four



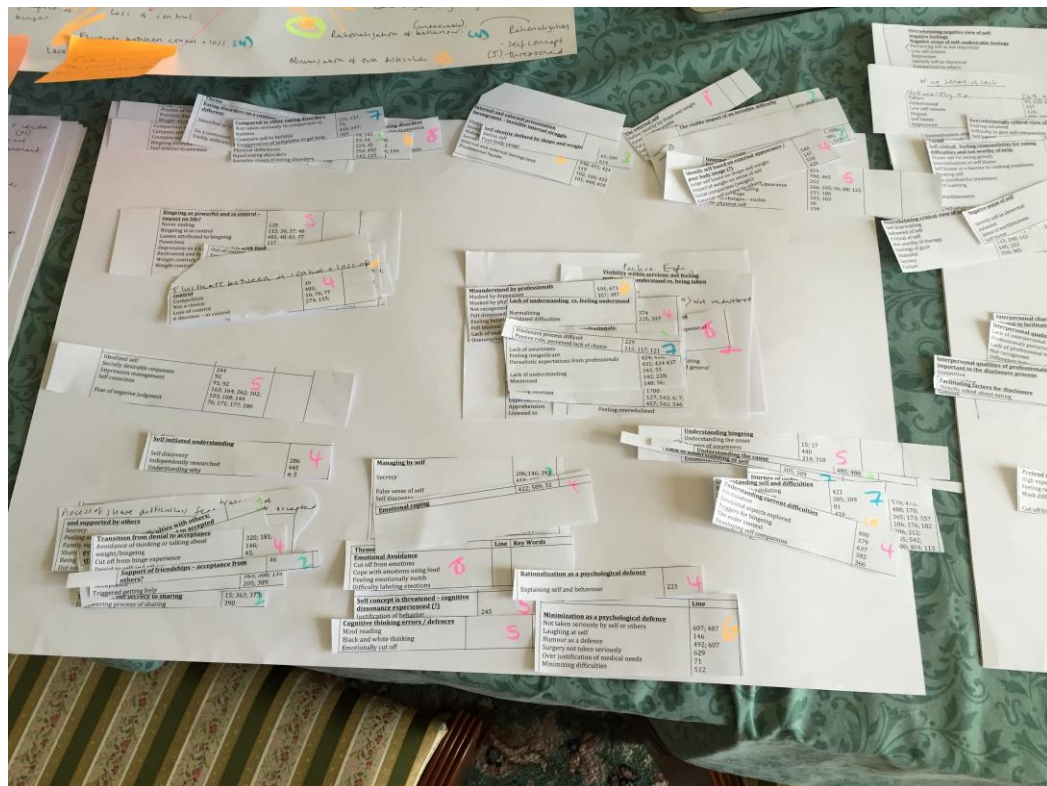
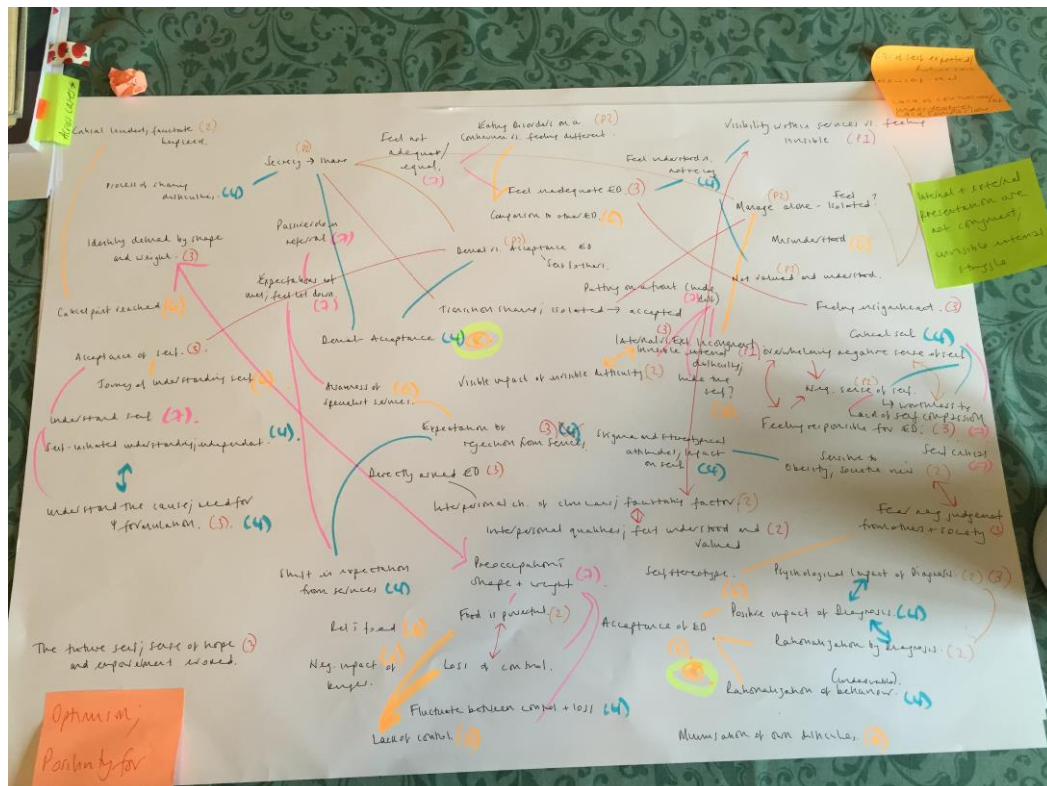
### Appendix Q: Example of Emergent Theme Table (Participant Four)

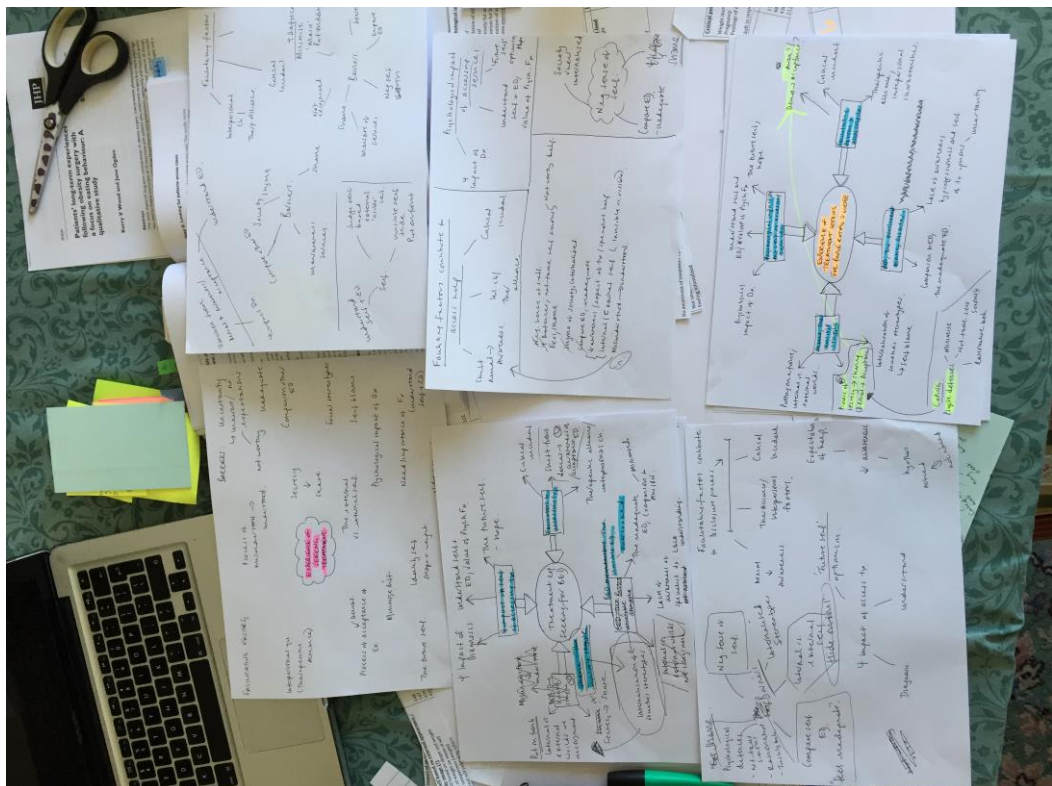
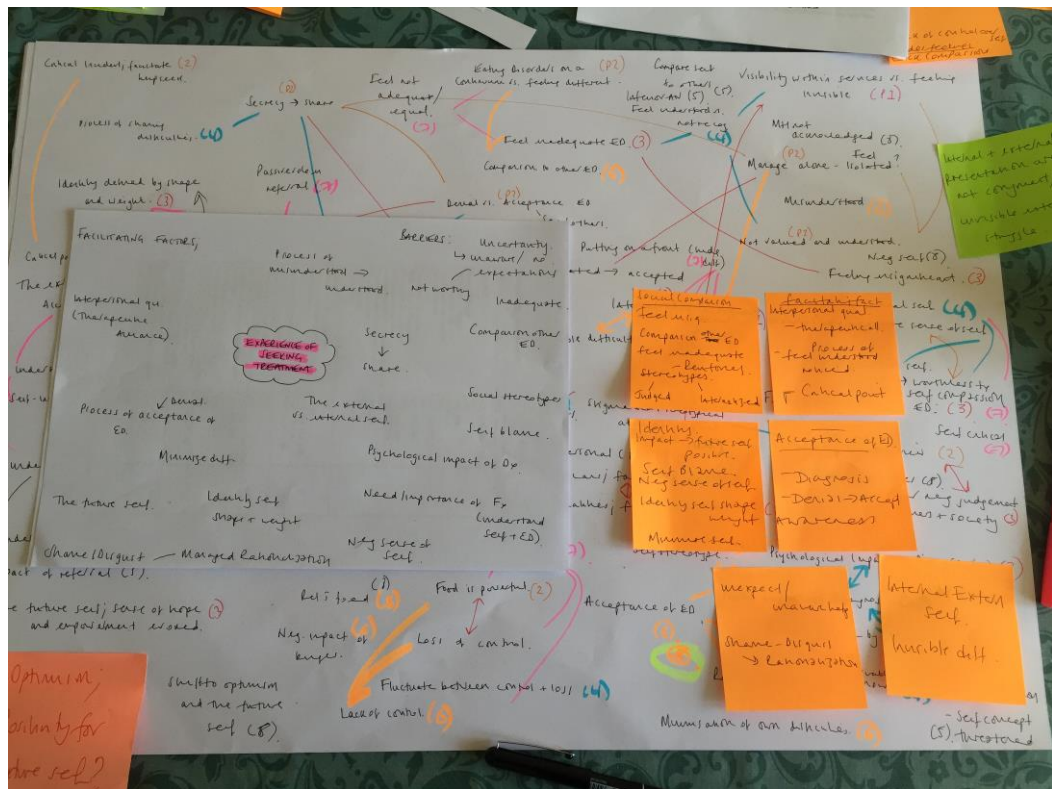
Theme	Line
<b><u>Psychological impact of diagnosis</u></b>	
Relief	153
Validation of difficulties	370; 372; 471
Denial	183; 129;
Necessity for accessing services	155
Optimism for help	471
Transition of acceptance	155; 188
Stigma associated	132
<b><u>Self initiated understanding</u></b>	
Self discovery	286
Independently researched	445
Understanding why	4; 5
<b><u>Rationalization as a psychological defence</u></b>	
Explaining self and behaviour	221
<b><u>Identify self based on external appearance / poor body image (?)</u></b>	
Judge self based on shape and weight	548
Impact of weight on sense of self	547
Social comparison (weight)	550
External self judged by others	420
<b><u>Understanding current difficulties</u></b>	
Formulation	400
Emotional aspects explored	379
Triggers for bingeing	637
The wider context	382
Developing self compassion	366
<b><u>Transition from denial to acceptance</u></b>	
Avoidance of thinking or talking about weight/bingeing	320; 181; 146;
Cut off from binge experience	45;
Denial to self and others	86; 191
Self initiated disclosure	141
Acceptance	363; 368; 135
Triggered getting help	205; 389
<b><u>Negative sense of self</u></b>	
Identify self as abnormal	48
Ashamed	54; 25; 41
Sense of worthlessness	327
Self blame	
<b><u>Fluctuate between being in control and loss of control</u></b>	
Compulsion	
Not a choice	39
Loss of control	405;
A decision – in control	16; 76; 77
	274; 115;
<b><u>Change in expectation from services</u></b>	
Frustrated at system	241
Low expectations	270; 417; 244;
	249
Optimism for the future	324; 347
Justify self	305
Fearful of no help	245
Value placed on specialist services	260; 263; 257;
	496
No awareness of treatment options	417

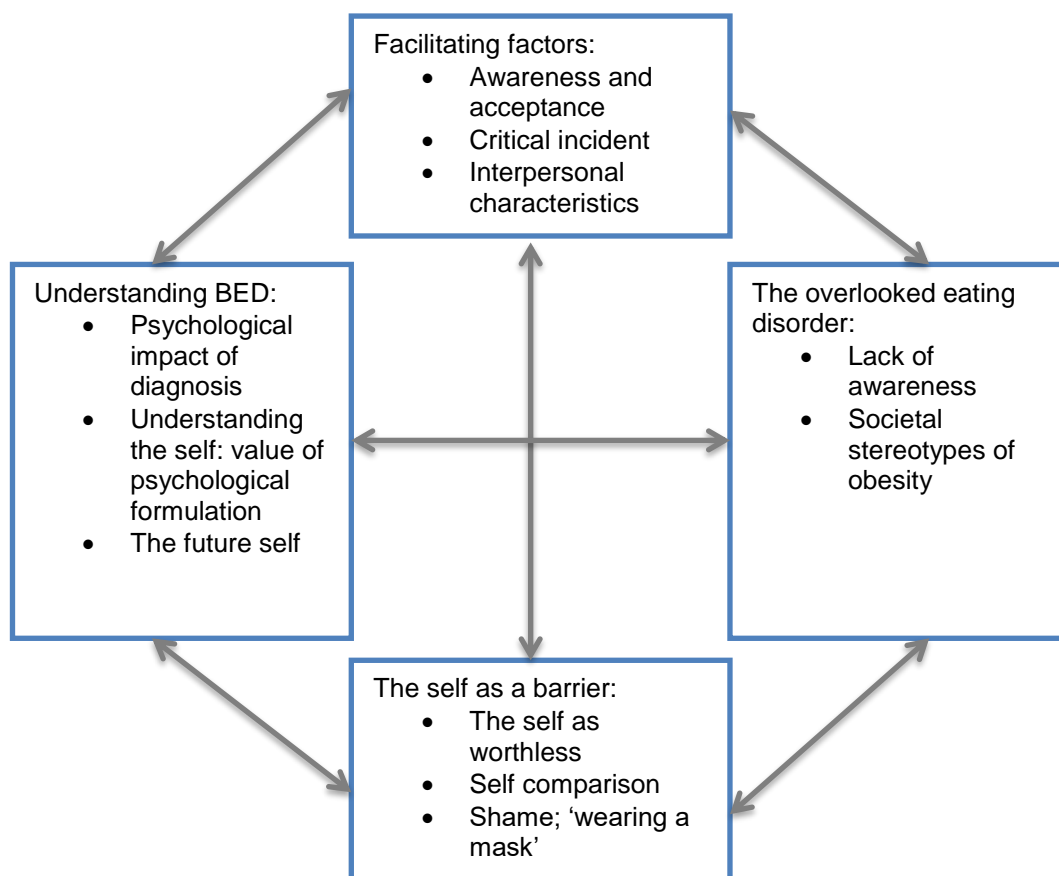
Theme	Line
<b><u>Process of sharing difficulties</u></b>	
False sense of self	51; 59; 82
Secrecy	69; 9; 184
Isolated	460;
Ashamed	19; 20
Supportive	458
Inclusive	358;
Relief	349
Interpersonal qualities to feel safe	225
<b><u>Stigma and stereotypes</u></b>	
Fear of discrimination	170
Negative judgment from others	483; 174
Media representations of obesity	430
Assumed bulimic	212
<b><u>Lack of understanding vs. feeling understood</u></b>	
Normalisation	374
Validated difficulties	225; 337
MDT	236
Relief	349
Overemphasised medication	118; 199
Lack of awareness	453; 442; 434; 220
Not identified as psychological	437; 292; 428
Taken seriously	399;
Feeling dismissed	230
Anticipated not understood	244  249
<b><u>Emotional coping</u></b>	422; 589; 32



## Appendix R: Example of the Development of Connections between Emergent Themes across Participants





**Appendix S: Inter-relationships between Super-ordinate Themes**



# Appendix T: Eating Disorder International Conference (EDIC) 2016 Conference Poster



## Treatment Seeking for Binge Eating Disorder: An Interpretative Phenomenological Analysis

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### INTRODUCTION

Binge Eating Disorder (BED) was introduced as a separate eating disorder (ED) in the fifth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2013). It is widely recognised that a low proportion of individuals with ED receive treatment and that there is a large unmet need within the community (Hart, Granillo, Borm, Paxton, 2013). This delay in receiving ED treatment has been reported to be approximately five years (Rosenvinge & Klusmeier, 2000). Whilst BED has been estimated to be the most prevalent of the ED, it is not widely recognised (Turner, 2013).

Barriers to treatment seeking for ED include, shame and denial of illness, concerns about negative judgements from others, poor symptom knowledge, fear of stigma (Hepworth & Paxton, 2007; Goodwin & Fitzgibbon, 2000).

Facilitating factors have included, increased psychological distress, increased perceived symptom severity, increased awareness, others initiating the process, interference with everyday activities and when self management is no longer effective (Gilbert et al., 2012; Schoen et al., 2012; Hepworth & Paxton, 2007).

Qualitative studies have explored the process of accessing treatment for individuals with anorexia nervosa (AN) and ED (Gulliksen et al., 2015; Schoen et al., 2012) however there is a paucity in the literature pertaining specifically to BED and to date, no studies have considered the treatment seeking experience for BED specifically.

**Research aim:** to explore individuals' lived experiences of seeking treatment for BED.

### METHODOLOGY AND RESULTS

Table 1. Demographic information		
Gender	Female	83
	Male	03
Body Mass Index (BMI)	Mean	36.93
	Range	26.9-48.4
Time since diagnosis	Mean	29 years
	Range	7 days-30 years
Ethnicity	White British	83
Marital status	Married	30
	Singled	48
	Separated	13
Occupation	Full time	40
	Part time	29
	Unemployed	13
	Student	13

Eight participants were recruited from specialist NHS outpatient ED Service. Participants were interviewed using a semi-structured interview, which was developed using service user consultation. Interviews ranged between 32-56 minutes in duration. The data was analysed using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). This led to the development of four super-ordinate themes and 11 sub-ordinate themes (Figure 1).

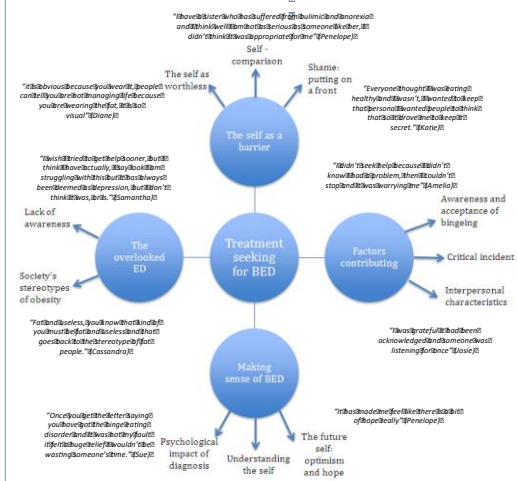


Figure 1. Super-ordinate and sub-ordinate themes

### RESULTS AND DISCUSSION

All participants experienced difficulties in their journeys to access specialist treatment. They had all attempted several times without success before receiving specialist help for their eating difficulties.

Specific difficulties in accessing treatment included identification of the self as not worthy of treatment, social comparison and shame attached to eating difficulties ('the self as a barrier'). Participants experienced incongruence between their internal and external worlds and shame related to bingeing. Shame has been accepted as a central phenomenon in ED, shame has been found to be related to bingeing and purging behaviour in bulimic individuals (BN).

This was reinforced by contextual factors, which appeared to further impede access to treatment, described as the 'overlooked eating disorder' theme. Emotional overeating and eating are different to ED and this is not widely recognised and indeed was experienced by participants. Information relating to binge eating disseminated in the public domain is frequently discussed in the context of obesity (Turner, 2013).

Facilitating factors, included interpersonal factors, which contributed to feeling understood, the process of awareness and critical incidents (factors contributing to accessing treatment), this led participants to feel able to initiate the treatment seeking process and to disclose their difficulties.

Finally, 'making sense of BED' as a consequence of accessing treatment was considered, this was encompassed within the themes of the psychological impact of receiving diagnosis, understanding the self, and the future self.

### CLINICAL IMPLICATIONS

- This is the first study to have used qualitative methods to explore the experience of seeking treatment and to have identified shame as a barrier to accessing treatment for BED and indeed for sharing difficulties with professionals. This is important for clinicians in both primary and secondary care services to be aware of when individuals present at their clinics.
- Participants described initially seeking treatment for physical and/or psychological difficulties other than their eating concerns. In addition to interpersonal characteristics in professionals participants valued being asked direct questions about their eating patterns. This is an important opportunity for clinicians to ask questions about eating and to assess for BED given that individuals may not initiate dialogue regarding eating patterns.
- Insight into the treatment seeking experience from participants who have successfully accessed treatment allows information regarding the facilitating factors in addition to barriers to be explored, and to consider how these can be applied within primary care and community settings.
- The experiences of shame and self-criticism described in this study suggest that compassion focused therapy (CFT) (Gilbert, 2010) might be of clinical benefit for this client group, as this particular therapy aims to evoke self-compassion in individuals.
- The lack of awareness from both professionals and individuals about BED symptoms suggests that there is a need for educating both individuals and professionals about the criteria and characteristics of BED.

### Contact

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