An Exploration of Eating Disorders in Different Populations

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

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List of Abbreviations and Symbols

AN- Anorexia Nervosa

BAME- Black Asian and Minority Ethnic

BED- Binge Eating Disorder

BMI- Body Mass Index

BN- Bulimia Nervosa

BPS- British Psychological Society

CBT- Cognitive Behavioural Therapy

CGT- Constructivist Grounded Theory

DE- Disordered Eating

DEB- Disordered Eating Behaviour

DKA- Diabetic Ketoacidosis

DSM-IV- Diagnostic and Statistical Manual of Mental Disorders-IV

DSM-V- Diagnostic and Statistical Manual of Mental Disorders 5

ED- Eating Disorders

EDNOS- Eating Disorder Not Otherwise Specified

GP- General Practitioners

HbA1c- Haemoglobin A1c

LGBTQIA- Lesbian, Gay, Bisexual, Transgender, Queer, Intersex and Asexual

NHS- National Health Service

NICE- National Institute for Health and Care Excellence

PICo- Population, Phenomena of Interest and Context

PRISMA- Preferred Reporting Items for Systematic Review and Meta-Analyses

PTMF- Power Threat Meaning Framework

SES- Socioeconomic Status

TOD- Type One Diabetes

UK- United Kingdom

USA- United States of America

WHO- World Health Organization

Symbols

κ – Kappa Coefficient

p – probability value

r^2 – Coefficient of Determination

r – Pearson Correlation

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To all my close friends and family, those who have offered endless amounts of encouragement, words of support, late-night pep talks, prayers and a variety of care packages. I am eternally grateful. To my mum and dad, my biggest supporters, thank you for encouraging me to persevere always. To my daughter, my favourite person on this earth. I love you so very much. You have been amazingly patient, and I owe you BIG!

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Declaration

This thesis has been submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology at the Universities of Coventry and Warwick. The work presented has been completed and written by myself as an original piece of work, conducted under the academic supervision of Dr Carolyn Gordon (Academic Tutor, Doctorate Programme in Clinical Psychology, Coventry University and University of Warwick) and Dr Jo Kucharska (Clinical Director/Senior Lecturer, Doctorate Programme in Clinical Psychology, Coventry University and University of Warwick). Chapter One of this thesis has been written in preparation for submission to the Journal of Diabetes and Its Complications. Chapter Two has been written in preparation for submission to the Journal of Cross-Cultural Psychology.

Word Count (excluding, abstracts, tables, figures, references and appendices)

Chapter One: 8,315

Chapter Two: 8,398

Chapter Three: 3,266

Total: 19,979

Summary

This thesis is compromised of three chapters. Chapter One is a narrative synthesis exploring the risk factors associated with the development of eating disorders in young people with Type One Diabetes. Identified risk factors were grouped into three themes: Biological, Physiological and Psychosocial, with corresponding sub-themes. The findings indicated that the risk factors identified could inform screening measures, psychoeducation and preventative strategies regarding eating disorders in young people with Type One Diabetes.

Chapter Two is an empirical qualitative study exploring how young Black British women conceptualise eating disorders and disordered eating. Using a constructivist grounded theory approach a relational model was developed which illustrates the systems that Black women encounter throughout their lives that influence their understanding of; the concepts of food, eating, eating disorders and disordered eating. Clinical implications in relation to the identification and treatment of Black women with eating disorders and disordered eating are explored.

Chapter Three is a reflective paper employing the Power Threat Meaning Framework to explore the author's experiences and reflections whilst conducting thesis research. This chapter covers challenges experienced by the author in topic selection and undertaking remote interviews. Additionally, the author considers parallel experiences between themselves and participants and the implications of the social justice conversations happening across the world.

Chapter One

The Risk Factors Involved in the Development of Eating Disorders in Young People with Type One Diabetes: A Narrative Synthesis

This paper will be adapted for submission to the Journal of Diabetes and Its Complications (see Appendix A for author guidelines)

Overall Chapter Word Count (excluding abstracts, tables, figures, references and appendices): 8,315

Abstract

The present review set out to critically evaluate and synthesise empirical evidence regarding the risk factors associated with young people with Type One Diabetes for developing eating disorders. Six databases (Medline CINAHL, Pubmed, EMBASE, APA PsycINFO and Scopus) were systematically searched using the terms guided by the scope and aim of the review. A total of sixteen studies met the inclusion criteria and were synthesised using a narrative approach. The results were structured into themes; Biological, Physiological and Psychosocial risk factors, with corresponding sub-themes. The findings indicate that there is a risk profile that can be identified in young people with Type One Diabetes for developing eating disorders such as: being female, higher HbA1c levels, increased body dissatisfaction and disease specific risk factors such as disruption to satiety. The findings from this review highlight the importance of incorporating mental health care within the management and treatment of chronic physical health conditions. Effective management of Type One Diabetes within young people could include integrating psychoeducation around eating disorders and preventative strategies as standard practice.

1.0 Introduction

1.1 Review Subject and Significance

This review will address the area of Eating Disorders (ED) in young people with Type One Diabetes (TOD). The World Health Organisation (WHO) refers to young people as those who are aged between 10-24 (WHO, n.d). Eating Disorders (ED) refers to the four diagnostic categories as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013). These are: Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED) and Eating Disorder Not Otherwise Specified (EDNOS). However, there are other forms of eating distress that do not meet this criterion due to being at a lesser frequency or lower severity than is considered pathological (Neumark-Sztainer et al., 2011). This is commonly referred to in the literature as Disordered Eating (DE; Neumark-Stzainer et al., 2011). For the purposes of this review DE and the associated Disordered Eating Behaviours (DEB) will be included under the umbrella term ED.

TOD, also known as Diabetes Mellitus or Insulin Dependent Diabetes Mellitus is one of the most common chronic conditions of childhood and adolescence (Gale, 2005); it is an autoimmune disease that prevents the body from being able to produce enough insulin to adequately regulate blood glucose levels. Those affected by TOD typically adhere to a treatment regimen that includes; regular blood glucose measurements, insulin administration by injection or pump, careful monitoring of food content and intake, and regular medical check-ups. In the United Kingdom (UK) there are around 3.9 million people with a recognised diagnosis of diabetes and a further one million who are undiagnosed (Diabetes.org.uk, 2021). This equates to roughly 6% of the general population and TOD accounts for around 15% of the diabetic population (Diabetes.org.uk, 2017). There are over 25,000 people under the age of 25 with diabetes and around 97% of them have TOD (Royal College of Paediatrics and Child Health, 2009). Many long-term health problems associated with diabetes are preventable with proper treatment and care. However, if not managed properly TOD increases the chances of heart disease, stroke, circulation problems, neuropathy, retinopathy and kidney problems (Diabetes.co.uk, 2016).

Furthermore, there are psychological and social implications of living with a chronic illness. Reynolds & Helgeson's (2011) meta-analysis showed that young people reported more depressive symptoms and elevated anxiety levels. The cost of diabetes to the National Health Service (NHS) is an estimated £1 billion per year and around 80% is spent on diabetes complications (Diabetes.org.uk, 2017). Recent analysis of the impact of diabetes in the NHS estimated that TOD has three times as much impact as Type Two Diabetes (Stedman et al., 2020).

EDs are a complex psychological condition that affects people of all ages, genders and ethnic backgrounds. An ED is characterised by use of DEB, heightened concern regarding body weight and shape and in some (but not all) instances, very unhealthy weight loss (Polivy & Herman, 2003). DE can include some of the symptoms associate with EDs. They may also include aspects of self-esteem and self-worth based primarily on body weight or shape, a focus on excessive or rigid exercising, obsessive calorie counting, anxiety around certain foods and a rigid approach to eating or abnormal eating patterns (Nightingale & Cassin, 2019). ED prevalence is estimated at 2.2% in Europe which equates to an estimated 700,000 people in the UK, of which around 90% are female (Galmiche et al., 2019). EDs are devastating disorders associated with severe medical complications including vitamin deficiency, tooth decay and organ damage (Dickstein et al., 2014). AN has the highest mortality rate of any psychiatric disorder (Arcelus et al., 2011) due to medical complications and suicide rates. A study by DeJong et al. (2013) showed that in comparison to the rest of the population, people with EDs have a markedly decreased quality of life.

The prevalence of ED and DEB have been shown to be significantly higher in individuals across all ages with TOD, compared to the non-diabetic population (Herpertz et al., 1998). A meta-analysis of studies showed that 7% of adolescents with TOD had an ED compared to 2.8% without TOD (Young et al., 2013). The same meta-analysis found a higher proportion of adolescents with TOD were classified as having DEB, 39.3% compared to 32.5% without TOD (Young et al., 2013). The reported prevalence of sub-clinical DEB in TOD is estimated to be up to 40% (Young et al., 2013). EDs in TOD is associated with

poorer glycaemic control (levels of blood sugar), more frequent episodes of diabetic ketoacidosis and higher rates of diabetes related microvascular complications such as retinopathy (Colton et al., 2015). In a study by Goebel-Fabbri et al. (2008), women who restricted insulin (to manage weight) had a mortality rate three times higher than those who did not. Nielsen et al. (2002) found that the death rates from the combination of AN and TOD were 35% over the studies ten-year period, compared to 6.2% for AN alone and 2.5% for TOD alone.

As with any phenomena there is a propensity to want to understand aetiology. It is suggested that TOD increases the risk of developing an ED indicated by the higher prevalence rates of ED amongst individuals with TOD (Colton et al., 2009). Individuals with TOD may be more prone to developing issues related to food and weight, given that they are required to pay close attention to their weight, meal planning, food portions and food intake in order to monitor the amount of insulin they require (Logan-Stotland, 2006). The focus on dietary concerns intrinsic to TOD management, also leaves this population more at risk of an ED going undetected, as it can be masked as or mistaken for, part of diabetes management (Pereira & Alvarenga, 2007). Additionally, insulin omission is a unique behaviour displayed by individuals with TOD as an attempt to prevent weight gain. This is known colloquially as “Diabulimia”; although not an official medical diagnosis, it is a recognised as a specific type of ED that only affects those with TOD (Larrañaga et al., 2011).

As would be expected, comorbid EDs and TOD are associated with serious medical risks and premature mortality (Hanlan et al.,2013). Scheuing et al. (2014) evaluated over 500,000 TOD patients and found that 467 had a recognised ED. Pursey et al. (2020) found the validity of screening tools used to assess DEB in TOD were overall poor in quality with a high risk of bias.

Puberty and adolescence are stages of life characterised by numerous cognitive, physiological and social changes. This developmental stage is associated with increased independence, more risk behaviours and social comparison and peer influence (Kipke, 1999). According to Diabetes UK (n.d.) TOD is often diagnosed between the ages of four and fourteen years old, with a peak occurring

between 10-14 years old. ED statistics show that those aged between 14-25 are most at risk for developing an ED (anorexiabulimiacare, 2016). It could be argued for this reason, that young people with TOD are the key demographic in which to explore ED risk.

Identifying risk factors amongst this population may create better prevention strategies, aid quicker clinical detection of EDs by highlighting specific areas of interest, inform more effective targeted treatment and possibly prevent medical complications in the future.

1.2 Evaluation of Previous Reviews

There are systematic reviews that have addressed EDs in individuals with TOD regarding prevalence, quality of screening tools and psychological interventions. Young et al. (2013) and Mannucci et al. (2005) meta-analyses focused on the prevalence of EDs and BEDs between diabetic and non-diabetic subjects. Young et al. (2013) noted that EDs and DEBs were more common in adolescents with TOD compared to their peers. Mannucci et al. (2005), reported that the prevalence of AN was not significantly higher in females with TOD compared to controls, however, the incidence of BN was significantly higher in adolescent and adult females with TOD. Both Young et al. (2013) and Mannucci et al. (2005) suggested routine screening for eating problems in adolescents with TOD. Furthermore, Young et al. (2013) recommended that future work should focus on identification predictors of eating problems in young people with TOD.

The validity and reliability of measures used in assessing EDs and DEBs in TOD was questioned by Young et al. (2013) and Mannucci et al. (2005). Pursey et al.'s systematic review regarding the quality of screening tools used to identify DE within the TOD population supported this and authors suggested there was a need for greater sensitivity on these measures (Pursey et al., 2020).

Banting and Phillips (2018) explored the impact of psychological treatment within this population and concluded that individualised intervention addressing the difficulties of both TOD and EDs are most

effective. They also highlighted that within the TOD population the identification of risk will be the most important factor for early intervention support (Banting & Phillips, 2018).

The above systematic reviews were robust and thorough in their exploration of EDs within the TOD population. However, the main research aims or focus of these reviews did not relate directly to identifying risk factors of ED in TOD. Additional review articles exist within this area, Peterson et al. (2014) presented a novel theoretical risk model addressing correlates of EDs in youth with TOD. Although the review's aim was specific, literature searches were not conducted on appropriate databases and there was no quality appraisal of the literature using a validated quality assessment framework (Greenhalgh, 1997). Furthermore, the risk factors for developing EDs in TOD have been addressed in broad review articles (Hanlan et al., 2013; Pinhas-Haimel et al., 2015). Such overviews are considered to be subject to more bias and lack the critical robustness of a systematic literature review (Jahan et al., 2016).

1.3 Rationale and Aim of Current Review

Previous reviews have addressed a range of topics related to the comorbidity of ED and TOD and highlighted the importance of investigating risk factors of developing EDs and DEBs in TOD further (Banting & Phillips 2018; Mannucci et al., 2005; Pursey et al., 2020; Young et al., 2013 &). Although review articles have summarised potential risk factors for EDs within a TOD population (Hanlan et al., 2013; Peterson et al., 2014 and Pinhas-Haimel et al., 2015) these have not employed a systematic analytical strategy. Therefore, there is no systematic review that has synthesised the identifiable risk factors associated with developing an ED with TOD. Additionally, Mannucci et al. (2005), Young et al. (2013), Banting and Phillips (2018) and Pursey et al. (2020) rely heavily on quantitative data. Qualitative studies may be invaluable in understanding the specific vulnerabilities faced by individuals with TOD in developing EDs. The narratives from young people or carers may provide additional information regarding context such as individual variability to a complex clinical condition.

The prevalence of EDs in TOD and recent empirical research suggests that a systematic review of literature regarding risk factors is merited in order to draw conclusions for clinical practice (Petticrew & Roberts, 2012). This may potentially inform early intervention strategies or facilitate prevention of EDs in TOD (Banting & Phillips, 2018). This current review proposes to utilise a mixed method narrative synthesis approach to integrate both qualitative and quantitative research designs. Furthermore, clearly defining the concepts being explored, should add to the robustness of the review.

The present review aims to critically evaluate current empirical research to answer the review question: What are the risk factors involved in the development of Eating Disorders in young people with Type One Diabetes?

2.0 Methods

2.1 Systematic Literature Search

An initial scoping search into EDs and TOD literature was conducted on Google scholar to determine the feasibility of the proposed topic. Following ethical approval from Coventry University Ethics Committee (Appendix B) a systematic literature review search of empirical studies exploring the risk factors associated with adolescents with TOD developing EDs was carried out during March 2021-April 2021. Databases were chosen based on their relevance to the proposed topic and included databases within the disciplines of medicine, psychology and nursing. The identified databases were; Medical Literature Analysis and Retrieval System Online (Medline), Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Excerpta Medica database (EMBASE), APA PsycINFO and Scopus. The reference lists of extracted articles were searched manually to identify other relevant articles. Additional searches of grey literature through the Google Scholar and Proquest dissertation and theses: UK and Ireland database and Manual reference searches were completed. The main search terms utilised are presented in Table 1.

Table 1

Key Search Terms

Main Concepts	Synonyms	Location
Young People	Teenager	Title
	Teenage	Abstract
	Youth	Keywords
	Adolescents	
	Young Person	
	Young Adults	
	Paediatric / Pediatric	
	Children	
Type One Diabetes	Diabetes Mellitus	Title
	Insulin dependent diabetes mellitus (IDDM)	Abstract
	T1D	Keywords
	Juvenile diabetes	
Eating Disorders	Anorexia Nervosa	Title
	Bulimia Nervosa	Abstract
	Binge-Eating Disorder	Keywords
	Binge-Eating	
	Eating Disorder Not Otherwise Specified (EDNOS)	
	Other Specified Feeing or Eating Disorder (OSFED)	
	Disordered Eating	
	Disordered Eating Behavior/Behaviour/Behaviours	
	Disordered Eating symptoms	
	Diabulimia	
	Eating Pathology	

Main Concept	Synonyms	Location
Risk	Risk Factors	Title
	Correlates	Abstract
		Keywords
		Main Text

Key search terms considered relevant to the review topic included the main concepts of adolescence, Type One Diabetes, eating disorders and risk. Each of these key terms had multiple synonyms to capture all relevant studies and the location of the key terms. The concept of risk was broken down into specific types of risk and synonyms for risk such as correlates and predisposing factors.

The reviewer employed Boolean operators to construct the following search strategy:

> (Adolescents OR teenage OR teenager OR youth OR young people OR young person OR young adult OR paediatric OR pediatric OR children) AND (Type One Diabetes OR T1D OR diabetes mellitus OR TOD OR Insulin dependent diabetes mellitus OR Insulin Dependent Diabetes Mellitus OR Juvenile diabetes) AND (eating disorder* OR anorexia nervosa OR bulimia nervosa OR binge eating disorder OR disordered eating OR disordered eating behaviours OR disordered eating behavior OR diabulimia OR eating pathology OR eating disorder symptoms OR Eating Disorder Not Otherwise Specified OR Other Specified Feed or Eating Disorder)AND (risk OR risk factors OR correlates).

The wildcard truncation * was used to capture variations in spelling. The operators “OR” and “AND” were used to combine and connect the concepts, this ensured that results were narrowed to literature containing the main concepts.

2.2 *Inclusion and Exclusion Criteria*

At the initial search stage Titles and Abstracts were screened and papers retained if they met the following criteria: (a) they were available in English language (b) they mentioned young people with Type One Diabetes and eating disorders, (c) they were empirical studies, (d) they had been peer reviewed, (e) they were conducted in 2000 or later. After the initial screening, full text articles were sourced and assessed against the inclusion and exclusion criteria (Table 3) for eligibility. The inclusion and exclusion criteria were informed by the PICo (Population, Phenomena of Interest and Context; Table 2) process that helped to inform the literature search strategy (McArthur et al., 2015).

Table 2

PICO Process

PICO	
Population (P)	Young people with Type One Diabetes
Interest (I)	Risk Factors
Context (CO)	Developing eating disorders

Table 3

Inclusion and Exclusion Criteria

Type	Criteria	Include	Exclude
	Study	Empirical Papers	Non-Empirical papers
		Grey Literature	Non-peer reviewed papers
	Country	All	Studies not published in the English language
	Time Period	2000-2021	Before 2000
Methodology	Epistemology	All	
	Research Design	Mixed	
	Method of Data Collection	Mixed	
	Sample Age	10-24	Under the age of 10
			Over the age of 24
			Studies were parent data could not be separated
	Sample Gender	Mixed	
Phenomenon	Type One Diabetes	Type One Diabetes/Diabetes Mellitus	Type Two Diabetes
		Insulin Dependent Diabetes Mellitus	Gestational Diabetes
		Juvenile diabetes	Diabetes LADA (Latent Autoimmune Diabetes of Adulthood)
			Diabetes MODY (Maturity Onset Diabetes of the Young
			Double Diabetes
			Type Three Diabetes
			Steroid induced Diabetes
			Secondary Diabetes
			Diabetes Insipidus

			Any other comorbid chronic illness
Type	Criteria	Include	Exclude
Phenomenon	Eating Disorders	Anorexia Nervosa	Feeding Disorders
		Bulimia Nervosa	Avoidant Restrictive Food Intake Disorder (ARFID)
		Binge-Eating Disorder	Pica
		Binge-Eating	Rumination Disorder
		Eating Disorder Not Otherwise Specified (EDNOS)	
		Other Specified Feeing or Eating Disorder (OSFED)	
		Disordered Eating	
		Disordered Eating Behaviours	
		Disordered Eating symptoms	
		Diabulimia	
		Eating Pathology	
Concepts	Risk Factors	Psychological	
		Psychosocial	
		Biological	
		Physical	
		Correlates	

The literature review only included empirical studies to have access to original data. Although an argument can be made that the underlying mechanisms of an ED may differ between countries and cultures the concept is thought to remain stable (Makino et al., 2004). Therefore, studies from different countries were included in the current review. Furthermore, all methodological types of studies were included to be aligned with the narrative synthesis approach. In keeping with the reported peak age ranges for TOD and ED, research of young people aged between 10-24 was included. The sample gender had no exclusionary criteria, including men within the review ensures that there is a representative sample of the target population. For a study to be elidable for inclusion

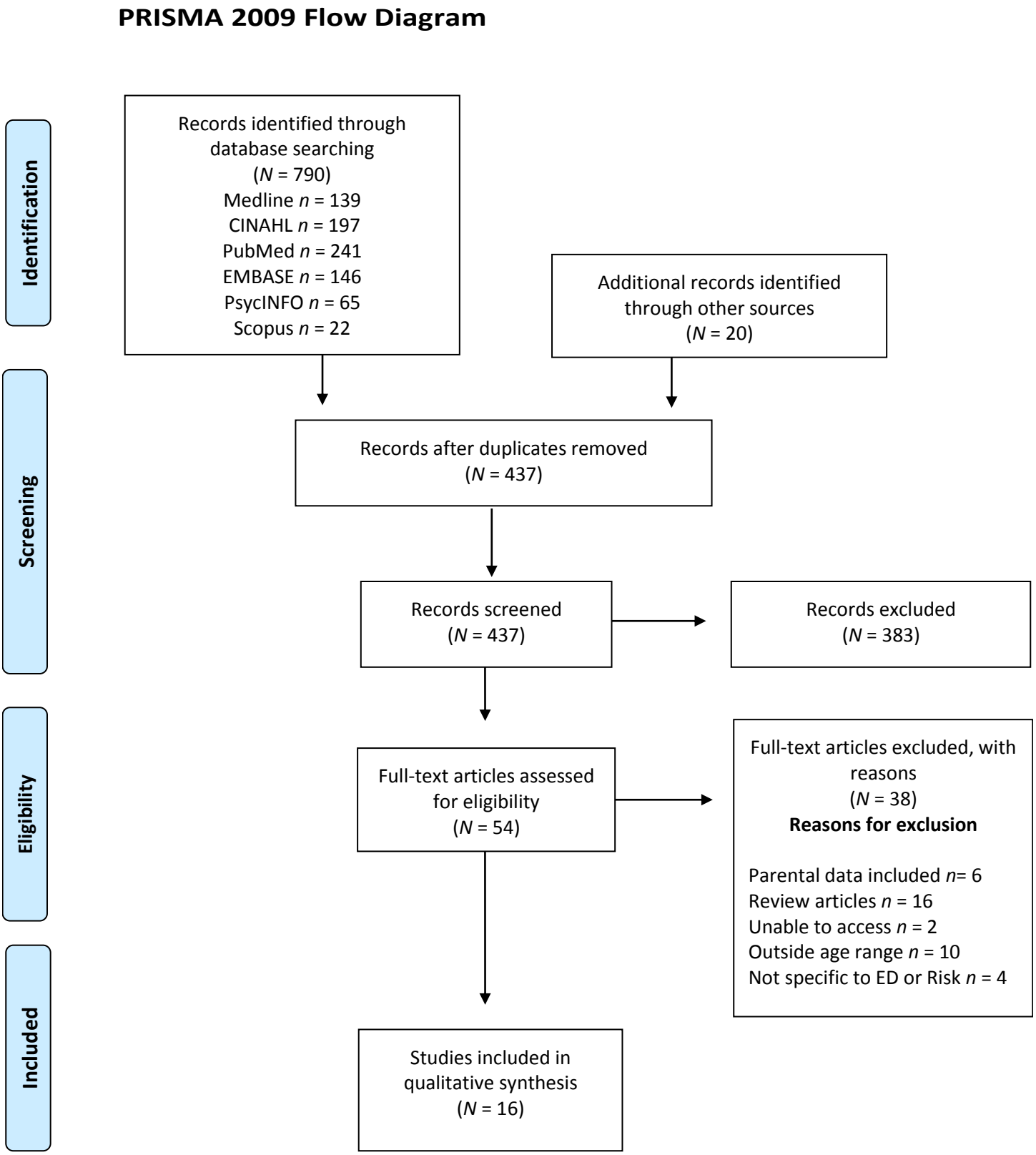
the main aim or primary focus needed to look at risk factors/correlates between TOD and EDs. Studies from 2000 to 2021 were included to reflect more contemporary definitions, understandings and practices within EDs and TOD. Finally, the current review excluded feeding disorders as they have a different psychological component than EDs. Avoidant Restrictive Food Intake Disorder (ARFID) was excluded because although there are anorexia-like symptomology present, it is not characterised by a drive for thinness, weight loss or body image concerns (DSM-5; American Psychiatric Association, 2013).

2.3 *Classification of Studies*

Study selection for this review was recorded using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009) flow diagram as shown in Figure 1.

Figure 1

PRISMA Flow Diagram of the study selection (Moher et al., 2009).



In total 790 articles were identified following the systematic search. An additional 20 articles were found through Google Scholar, Proquest dissertation and theses and a manual search of article references. Of these 810 articles, 373 were identified as duplicates and removed. The remaining 437 articles were subject to an initial screening of abstracts against the inclusion and exclusion criteria, after which a further 383 studies were excluded. The remaining 54 eligible studies were subject to a full text review and 38 were excluded based on; the inclusion of parents as subjects (where it was impossible to extract the data pertaining to young people), studies not being specific to the research aim, studies that included participants outside of the age range and review articles. This resulted in 16 studies being included in the final review.

2.4 *Quality Assessment Checks*

Caldwell et al. (2011; Appendix C) quality assessment framework was used to assess the quality of the 16 identified studies. This framework is applicable to both quantitative and qualitative research and suitable for health-related research (Caldwell et al., 2011). It consists of 18 criterion (quantitative) and 17 criterion (qualitative). Studies received scores of zero, one or two, dependent on whether the criterion was not met, partially met or fully met, ratings were then calculated by adding each criterion score together. Therefore, the maximum total score was 36 (for quantitative methodologies) or 34 (qualitative methodologies). A midpoint score of 17 or 18 was considered a satisfactory level of rigour and studies would have been excluded had they not met this level. However, all 16 studies scored between 20 – 32 (see Appendix D) and were therefore considered to be of good quality and appropriate for inclusion within the review.

In order to enhance reliability, a second researcher conducted independent quality assessment checks on the identified studies, using the same quality assessment framework (see Appendix E). To determine inter-rater reliability a Kappa coefficient statistical analysis was used, see Table 5. The Kappa reliability coefficient scores for the studies ranged between $\kappa = 0.7$ and $\kappa = 1.0$. According to

Hugh (2012) a Kappa score below 0.60 indicates inadequate agreement amongst independent raters. The scores in the current review are above 0.60 (see Appendix F) therefore, it can be assumed that there is evidence of strong and consistent inter-rater reliability.

2.5 *Analytic Review Strategy*

This review elected to take a narrative synthesis approach due to the heterogeneity of the studies included. A narrative synthesis adopts a textual approach to summarise and explain findings from multiple studies in order to "tell the story" of the current state of knowledge of a particular review area (Popay et al., 2006). The approach allows for qualitative and quantitative data to be included. Popay et al. (2006) outlined four key elements required for narrative synthesis and described specific techniques and tools that can be used. This guidance was aimed to address concerns regarding the lack of transparency and clarity about the process of the analysis and synthesis, therefore bias in the data collated (Dixon-Woods et al., 2005; Valentine et al., 2017). The key elements are outlined in Table 4.

Table 4

Key Elements of a Narrative Synthesis (Popay et al., 2006)

Key Elements	Aim
Developing a preliminary synthesis	To develop an initial description of the results of included studies
Exploring relationships within the data	To compare and contrast the ways in which results have been identified and analysed across the studies
Assessing the robustness of the synthesis	To assess the methodological quality of the studies included
Developing a (theoretical) model/map to explain findings	To provide an explanation of the interpretation of the review's findings

In line with Popay et al. (2006) the reviewer first developed a preliminary synthesis of the data. The central features and results of each study were collated into the Table of Study Characteristics (Table 5).

Thematic analysis is an appropriate technique for data analysis within a narrative review (Popay et al., 2006) and was conducted to identify the main, recurrent and significant themes across the identified studies (Mays et al., 2005). To assess robustness, studies underwent a quality assessment and critique, before an explanatory model was produced to illustrate how the included studies were related. The present review has applied the fundamental features of a narrative synthesis to explore and report research findings on the risk factors involved in developing EDs within young people with TOD by inductively extracting key themes.

3.0 Results

Table 5

Table of Study Characteristics

Author **Study Date** **Country** **Quality Assessment Rating (QR)** **Kappa Coefficient**	**Aims (Relevant to current study)**	**Research Design** **Sampling Method**	**Sample Characteristics** **Sample Size (N)** **Demographics:** **Where stated: gender; age; ethnicity; religion; socio-economic status; attendance of school/college**	**Method of Data Collection & Analysis**	**Key Findings**
Araia et al., 2020 Australia QR =89% *κ* = 1.000	Explore potential risk and protective psychological correlates for DE in youth with TOD by considering general and diabetes-specific risk factors, including diabetes distress and diabetes related resilience.	Quantitative Cross-Sectional Purposive sampling	*N*=477 Age: 13-19 years 15.7 ± 1.9 Female *n* = (62%) Male *n* = (38%) Australian born *n* = (93%)	National Online Survey Measures used: - Diabetes Eating Problem Survey-Revised[1] (DEPS-R; Markowitz et al., 2010) - Body Mass Index Silhouette Matching Test[2] (BMI-SMT; Peterson et al., 2003)- with additional study specific item.	Bivariate analysis: - DE correlated significantly with symptoms of depression (females *r*=.65; males *r*= .49, *p* < .001) and anxiety (females *r* = .57; males *r*= .45, *p* < .001), diabetes distress - (females *r*= .72; males *r* = .61, *p* < .001), and body dissatisfaction (females *r* = .67; males *r*=.42, *p* < .001) . - Inversely, disordered eating correlated negatively with

[1] Diabetes Eating Problem Survey Revised (DEPS-R): 16-item diabetes-specific self-report measure of disordered eating that can be completed in less than 10 minutes
[2] Body Mass Index Silhouette Matching Test (BMI-SMT): a measure to assess distortion in visual perception of one's own body, weight perception and perception of BMI.

	Attending school
	
	n = (80%)
	
	Paid employment
	
	n = (42%)
	
	Two parent Family structure
	
	n = (85%)
		- Patient Health Questionnaire for Adolescents[3] (PHQ-A; Johnson et al., 2002)
		- Generalised Anxiety Disorder Scale[4] (GAD-7; Spitzer et al., 2006)
		- Problem Areas in Diabetes Scale for teenagers[5] (PAID-T; Weissberg-Benchall & Antisdel-Lomaglio, 2011)
		- MIND Youth Questionnaire[6] (MY-Q; De-Wit et al., 2012)
		- World Health Organization-Five Well-Being Index[7] (WHO-5; Bech et al., 2003)
		- Diabetes Strengths and Resilience Scale[8] (DSTAR; Hillard et al., 2017)
		- Demographic & clinical information:
		  - Age
		  - Gender,
		  - Haemoglobin A1C (HbA1c; Glycated Haemoglobin)
		  - Diabetes management
		  - Height
		  - Weight
			general quality of life (females $r = -.50$; males $r = -.42$, $p < .001$), general emotional well-being (females $r = -.49$; males $r = -.36$, $P < .001$), and diabetes s-specific resilience (females $r = -.58$; males $r = -.45$, females, $p < .001$; males $P < .01$)
			
			Hierarchical multiple regression:
			
			- All of the predictors (female gender, age, HbA1c, BMI, diabetes-related resilience, general emotional well-being, diabetes distress, anxiety, body dissatisfaction) contributed significantly to the model at each step.
			- Step 1- female gender & age ($r = .39$, $p < .001$)
			- Step 2- female gender, age, HbA1c, BMI ($r = .56$, $p < .001$)
			- Step 3- female gender, age, HbA1c, BMI, diabetes-

[3] Patient Health Questionnaire for Adolescents (PHQ-A): Nine item measure to assess depressive disorders and episodes (or clinically significant symptoms) in children aged 11-17.
[4] Generalised Anxiety Disorder Scale (GAD-7): Seven item, self-report anxiety questionnaire designed to assess a person's health status during the previous two weeks.
[5] Problem Areas in Diabetes for Teenagers (PAID-T): 61-item measure to assess diabetes specific emotional distress in teenagers with type one diabetes.
[6] MIND Youth Questionnaire (MY-Q): 36-item questionnaire designed to assess health-related quality of life in teenagers and young people with diabetes.
[7] World Health Organisation – Five Wellbeing Index (WHO-5): Self-report measure of current wellbeing suitable for children aged nine and above.
[8] Diabetes Strength and Resilience Scale (DSTAR): 12-item self-report measure of adaptive attitudes and behaviours related to living with type one diabetes for young people aged 14-18.

					related resilience, general emotional wellbeing (r = .70, p < .001) - Step 4- female gender, age, HbA1c, BMI, diabetes-related resilience, general emotional wellbeing, diabetes distress, anxiety (r = .80, p < .001) - Step 5- female gender, age, HbA1c, BMI, diabetes-related resilience, general emotional wellbeing, diabetes distress, anxiety, body dissatisfaction (r = .84, p < .001) - Only HbA1c (p < .001), diabetes distress (p < .001), anxiety symptoms (p < .001), resilience (p < .05) and body dissatisfaction (p < .001), remained significant in the final model. - Of these, diabetes distress and body dissatisfaction had the strongest associations. - Overall, the final model explained 71% of the variance in DE.
Cherubini et al., 2018 Italy	Population-based study aimed to assess the prevalence of DEB of a region in Italy, using the Italian version of DEPS-R (Cherubini et al., 2018 Markowitz et al., 2010) as a screening tool. The study hypothesized that age,	Quantitative Cross-sectional Purposive Sampling	*N*=163 Italian Youth Age: 11-20	Survey Measures Used: Diabetes Eating Problem Survey-Revised. Italian Version	The characteristics of the study sample were evaluated according to the DEPS-R levels (≥20 and <20). - Group comparisons between those with

QR =92 % κ = .824	gender, BMI, physical activity, family socio-economic status, metabolic control, insulin restriction, insulin treatment modalities, are correlates of DEB in adolescents with type one diabetes.	Mean age: 15.4 Female *n* = (51%) Male *n* = (49%) Classified Underweight (UW) *n* = (4%) Classified normal weight (NW) *n* = (76%) Classified overweight (OW) *n* = (15%) Obese (O) *n* = (6%)	(DEPS-R; Cherubini et al., 2018; Markowitz et al., 2010) Demographic & Clinical information: - Age - Age at diabetes diagnosis - Gender - Weight - Height - Number of episodes of severe hypoglycaemia or ketoacidosis in the last three months - HbA1c (Glycated Haemoglobin) - Lipid profile (total cholesterol, HDL cholesterol, triglycerides) - Weekly hours of physical activity - Insulin therapy regimen- multiple daily injections/continuous subcutaneous insulin infusion (MDI/CSII), - Average total daily insulin dose during preceding week - Presence of celiac disease - Use of carbohydrate counting system	DEPS-R scores ≥20 and those with DEPS-R score <20 used a Wilcoxon-Mann-Whitley test or Fisher test for qualitative variables. - Prevalence of DEPS-R score ≥20 was 34% (no significant difference between male and female (p = .063) - Prevalence higher in OW/O group (66%) than UW/NW group (26%) Multiple correspondence analysis (Benzecri, 1973) identified a group of socioeconomic and clinical factors useful in identifying those adolescents with type one diabetes vulnerable to DEB that were associated with a DEPS-R score ≥20: - Higher HbA1c levels - Higher median total cholesterol - Higher doses of insulin - Significantly lower time in physical activity (2 hrs or less) - OW/O - More frequently females	

- Number of insulin shots/day
- Number of skipped insulin injections per week (as assessed by physician)

Family characteristics:

- Parents' age
- Parents' education
- Parent's position of occupation
- Parent's history of diabetes
- Low and medium family profile of education
- Low family profile of occupation

Multiple logistic regression analysis used to estimate the independent effect of patients sociodemographic and clinical characteristics on having a DEPS-R ≥20.

A DEPS-R score ≥20 was significantly associated with:

- HbA1c (p = .031)
- The number of skipped or forgotten insulin injections per week (p = .027)
- BMI (O/OW; NW/UW (p < .001)
- Time spent in physical activity (p = .001)
- In particular, the probability of having a DEPS-R score ≥20 increased about 63% for every added unit of HbA1c and about 36% for every added number of insulin injections skipped or forgotten in a week
- OW/O youth were more than six times more likely to have DEPS-R score ≥20 than those UW/NW.

					- The probability of a score ≥20 on DEPS-R decreased about 20% for every added hour per week spent in physical activity.
Eisenberg et al., 2016 America QR= 89% *κ* = 1.000	The purpose of the study was to examine associations of time-varying autonomous and controlled motivation with time varying DEB among adolescents with type one diabetes in the context of an 18-month behavioural nutrition intervention and to investigate whether baseline self-efficacy moderates these associations.	Quantitative Secondary Analysis of randomised clinical trial Longitudinal study design Purposive sampling	N=90 American youth Age: 13-16 Female *n* = (51%) Male *n*= (49%) White, non-Hispanic *n* = (91%) Hispanic *n* = (8%) Black, non-Hispanic *n* = (1%)	Questionnaires Measures used: Self-Efficacy for Healthy Eating[9] (Simmonds et al., 2015). Self-Regulation Questionnaire[10] (SRQ; Brown et al., 1999) Diabetes Eating Problem Survey-Revised (DEPS-R; Markowitz et al., 2010) Demographic & Clinical information: - Height - Weight - Gender	Bivariate Analysis: - DEBs positively correlated with controlled motivation (r = .63, p < .001) - DEBs negatively correlated with self-efficacy (r = -.33, p < .01) - DEBs showed no correlation with autonomous motivation - Autonomous motivation and controlled motivation positively correlated with each other. (r = .26, p < .05) Linear-mixed effects models tested the association of time-varying controlled and

[9] Self-Efficacy for Healthy Eating Scale: Eight-item measure to assess perceived ability to eat healthily.
[10] Self-Regulation Questionnaire (SRQ): 15-item measure to assess autonomous motivation, controlled motivation and amotivation for healthy eating among youth.

	- Age - Education level - Household income - Number of people in the home	autonomous motivation with time-varying DEB. DEBs were associated with: - controlled (β = 2.18 ± .33, *p* < .001), but not autonomous motivation (β = - .70 ± .43, *p* = .11) to eat healthfully. - There was also a statistically significant interaction of controlled motivation by self-efficacy to eat healthfully on DEB (β = -1.04 ± .40, *p* = .01). - Simple slope analysis indicated that the association of controlled motivation with DEB was stronger for those with lower self-efficacy (β = 3.33 ± .55, *p* < .001) than those with higher self-efficacy (β = 1.36 ± .36, *p* < .001) - There was no significant interaction of autonomous motivation by self-efficacy on DEB (β = - .84 ± .55,

					p = .12) - Neither age (*p* > .10) nor sex (*p* > .10) moderated the association of controlled motivation with DEB.
Grylli et al., 2005 Austria QR= 86% *κ* = .870	Aimed to explore temperament and character traits in adolescents with type one diabetes and to use the individual differences in temperament and character as statistical predictors of the occurrence of ED symptoms.	Quantitative Cross-sectional Purposive sampling	*N*= 199 (Self-Report) *n*=35 (Completed Interview) Austrian Youth Mean age: 14.2 Self-Report: Females *n* = (48%) Males *n* = (52%) Interview: Females *n* = (86%)	Questionnaire & Interview Measured Used: Eating Attitudes Test-26[11] (EAT-26; Garner et al., 1982) Eating Disorder Inventory II[12] (EDI-2; Garner, 1991) Eating Disorders Examination version 12.0[13] (Fairburn & Cooper, 1993)	11.5% of females and 0% of males met the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV; American Psychiatric Association, 1994). Two categories of EDs identified: ED-NOS & BN. Subthreshold EDs identified in 14% of females and 1% of males. - Participants with clinical or subthreshold EDs had significantly higher BMI than those without eating problems (*p* = .003).

[11] Eating Attitudes Test-26 (EAT-26): Psychological self-report assessment measure of symptoms and concerns characteristic of an eating disorder.
[12] Eating Disorder Inventory-2 (EDI-2): 91-item self-report measure designed to assess attitudinal and behavioural dimensions relevant to anorexia nervosa and bulimia nervosa.
[13] Eating Disorder Examination version 12.0: A measure of the range and severity of eating disorder features, designed to generate eating disorder diagnoses according to the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV).

	Males *n* = (14%) Average BMI: 20.4 (SD 3.3) Average duration of diabetes diagnosis 5.6 years (SD 3.4) All participants came from middle socioeconomic backgrounds. Two parent households *n* = (76%) Separated households *n* = (12%) Single parent households *n* = (12%)	Temperament and Character Inventory[14] (TCI; Cloninger et al., 1994) Children's Depression Inventory[15] (CDI; Kovacs, 1992) Demographic & Clinical information: - HbA1c - Parent's marital status - Parent's occupational status - BMI - Duration of diabetes diagnosis - How often seeing Paediatrician in the last year.	Significant differences by eating status were found in two of the seven standardized dimensions of temperament and character: self-directedness and harm avoidance. - Females with type one diabetes and a clinical or a subthreshold eating problem scored significantly lower on the dimension of self-directedness (p = .003) and significantly higher on the dimension of harm avoidance (p = .002). Binary logistical regression on Temperament and Character variables: - Harm avoidance (β = -.07, p = .02) and self-directedness (β = .08, p = .006) were significant predictor variables in

[14] Temperament and Character Inventory (TCI): Instrument for personality assessment to provide a comprehensive biopsychosocial model of personality across three dimensions of character and four dimensions of personality traits.
[15] Children's Depression Inventory (CDI): Instrument to measure the cognitive, affective and behavioural signs of depression in children and adolescents aged seven to seventeen.

					adolescents with a clinical ED than those without - Harm avoidance (β = -.08, *p* = .002) and self-directedness (β = -.06, *p* = .017) were significant predictor variables in adolescents with a subthreshold ED Possibility of having an eating disorder in the presence of these variables ranging from 88 to 97% for harm avoidance and from 101 to 111% for self-directedness. Conclusively, the presence of both could amplify eating disorders pathology in female adolescents with type 1 diabetes
Howe et al., 2008 America QR= 86%	The study objectives were (a) to report participants' score on the Diabetes Eating Problem Survey (DEPS) and its association with race, gender, age, BMI, haemoglobin A1c (HbA1c), weight satisfaction, and weight perception; (b) to describe participants' weight perception and weight satisfaction; and (c) to determine the prevalence of weight-control	Quantitative Cross-Sectional Survey design Purposive sampling	*N*= 295 American Youth Age: 11-20 Mean age: 14.9 (SD 2.5) Females *n* = (46%)	AHEAD survey Measures Used: Diabetes Eating Problem Survey (DEPS; Antisdel et al., 2001)	Participants' DEPS scores ranged from 32 to 81 (mean 48 ± 8.4). Stepwise multiple regression analyses were used to examine the relationship between DEPS score (total) as a dependent variable and participant age, age at diagnosis, BMI, HbA1c level, gender, race, weight perception, and weight

κ = .860	behaviours Weight Concerns in children with type one diabetes and the association of these behaviours with gender, age, BMI, HbA1c, weight satisfaction, and weight perception.	Males *n* = (54%) Mean age of diabetes diagnosis: 8.4 years (SD 4) White ethnicity *n*= (83%) Black ethnicity *n*= (13%) Hispanic *n*= (1%) Participants in middle school *n*= (42%) Participants in high school *n*= (44%) Participants post high school *n*= (13%) Participants not in school *n*= (2%) Two parent homes *n*= (79%) Single parent homes (mother) *n*= (16%)	Items from Project EAT survey[16] (Neumark-Sztainer et al., 2002) Demographic and Clinical Information: - HbA1c - Height - Weight - Parents education level	satisfaction as independent variables. - Weight satisfaction was statistically significant in predicting DEPS score ($p < .001$) - HbA1c was statistically significant in predicting DEPS score ($p < .001$) - In this model, when participants became dissatisfied with their weight, the DEPS score increased by 2.4 units ($t = 8.16$, $p < .001$), and for each percentage-point increase in HbA1c, DEPS increased 1.1 unit ($t = 4.18$, $p < .001$) - Scores were significantly associated with weight perception ($p < .001$) - DEPS scores significantly associated with weight satisfaction ($p < .001$)	

[16] Items from Project EAT Survey: Items assessing weight perception, weight satisfaction and weight control behaviours on a Likert scale, drawn from the original 221-item Project Eat Survey.

	Living with relative *n*= (2%)	- Participants who reported feeling overweight and/or reported being dissatisfied with their weight had evidence of more DEB as reported by DEPS scores (score of 53.4 vs. 46.1). Weight Perception and Satisfaction: - Overall 21.8% of participants reported that they were dissatisfied with their weight. More females reported being dissatisfied than males (39.4% vs 16.5%, *p*= .0001) Weight Satisfaction and Weight Control Behaviours: - 30.8% of participants were actively trying to lose weight, 12.5% trying to gain weight and 7.8% reported going on a diet more than five times. - Participants reported some unhealthy behaviours fasting 4.5% (*p*= .004), eating

little food 11.8% (p< .0001), using food substitutes 3.8% (p< .0001), skipping meals 10.4% (p< .0001) and smoking 1.4%.

- Very few reported the use of very unhealthy weight control behaviours, 1.4% diet pills, 1% vomiting, 1% skipped insulin, 1.4% laxatives (p= .0008), 1% taking less insulin and 0.3% diuretics.

Unhealthy weight control behaviours were associated with female gender:

- Eating little food (p= .000)
- Using food substitutes (p= .003)
- Skipping meals (p= 0.002)
- Increased smoking (p= .031)
- Using laxatives (p= .031)

Participants who perceived themselves as overweight engaged in significantly more unhealthy weight control behaviours:

- Fasting (p= .0003)
- Eating little food (p< .0001)

					- Using food substitutes (*p*= .0002) - Skipping meals (*p*< .0001) - Vomiting (*p*= .0100) - Using less insulin (*p*= .01) - Using laxatives (*p*= .0030) Additionally: - Mean BMI was significantly higher for participants who reported weight control behaviours. - Mean age for those who fasted was 16.7 years (*p*= .01) - Mean age for those who skipped meals was 15.8 (*p*= .03). - Those who skipped meals to lose weight had a higher mean HbA1c (*p*= .02) - HbA1c was higher for those who reported skipping insulin to lose weight (*p*< .001)
Kaminsky & Dewey 2013	The main purpose of the study was to investigate ED symptoms and body image in adolescents with type one diabetes. It was hypothesized that adolescents with type one	Quantitative Cross Sectional descriptive study	*N*= 46 Canadian youth Age: 12-18	Questionnaires Measures Used:	Chi squared analysis of variance used to investigate group differences on adolescents and family variables - No difference found between adolescents with type one

Canada QR= 92% κ = 1.000	diabetes would report significantly more symptoms of eating disorders and a less positive body image compared with adolescents without health problems	Purposive Sampling	Mean age: 15 years (SD 1.6) Female *n* = (50%) Male *n* = (50%) Ethnicity: Caucasian *n* = (90%) Other ethnic background *n* = (10%) *N*=27 (controls) Age: 12-18 Mean age: 14.9 years (SD 1.6) Female *n* = (48%) Male *n* = (52%)	Eating Disorder Inventory-3[17] (EDI-3; Garner, 1991) Body Esteem Scale for Adolescents and Adults[18] (BESAA; Mendelson et al., 2001) Social Support Scale for Children[19] (SSSC; Harter, 1995) Self-Perception Profile for Adolescents[20] (SPPA; Harter, 1988) Multidimensional Health Locus of Control Scale[21] (MHLC- Scale; Wallston et al., 1978) Pubertal Development Scale[22] (PDS; Carsakadon & Acebo, 1993)	diabetes and healthy comparison adolescents on any variables. Analyses of variance used to investigate group differences on body image and ED symptoms and differences in the measures of social self-concept, social support and locus of control. Regression analysis and correlations used to examine associations among measures of self-concept, social support and locus of control, and body image and ED symptoms. - Examination of predictors of body image showed that being male, higher levels of social support and a powerful others locus of control were associated significantly with a more positive body image on the BESAA (r^2 = 0.50, p < 0.001

[17] Eating Disorder Inventory-3: 91-item self-report measure designed to assess attitudinal and behavioural dimensions relevant to anorexia nervosa and bulimia nervosa.
[18] Body Esteem Scale for Adolescents and Adults (BESAA): 23-item body esteem questionnaire for adolescents and adults with 3 subscales.
[19] Social Support Scale for Children (SSSC): 24-item rating scale that assess children's perceptions of social support on four subscales.
[20] Self-Perception Profile for Adolescents (SPPA): self-report measure of psychosocial outcome in adolescents with chronic pain disorders.
[21] Multidimensional Health Locus of Control Scale (MHLC-Scale): 18-item scale measuring evaluating health locus of control on four dimensions.
[22] Pubertal Development Scale (PDS): Five-item self-report measure of pubertal status.

Correlation analysis conducted to investigate relationships between ED symptoms and body image.

- Correlations among the correlates (social support, self-esteem and locus of control) and outcome variables (EDI-III scales and body image scale) were calculated for adolescents with diabetes and healthy comparison participants separately. A higher powerful others external locus of control was correlated significantly with a more positive body image in adolescents with type 1 diabetes (r= 0.41, p= 0.01). In healthy comparison adolescents, higher levels of self-esteem were associated with a more positive body image (r= 0.44, p= 0.04), and higher levels of social support were associated with a lower drive for thinness

					(r= -0.41, p= 0.04) and fewer symptoms of bulimia (r= -0.43, p= 0.03). No other significant correlations were identified.
Meltzer et al., 2001 America QR= 83% κ = .769	The purposes of the study: 1) to examine body image and disordered eating attitudes and behaviours in a large sample of adolescents with Type 1 diabetes, 2) to identify predictors of body dissatisfaction and disordered eating and 3) to examine the relationship of disordered eating to glycemic control.	Quantitative Cross-sectional Purposive Sampling	*N*=152 American youth Age: 11-19 Mean age: 14.4 years Mean duration of diabetes: 6 years Female *n* = (54%) Male *n* = (46%) Ethnicity: White *n* = (82%) Black *n* = (9%)	Questionnaires Measures Used: Eating Disorders Inventory[23] (EDI; Garner et al., 1983) – two additional items related to insulin added. Subscales: Body Dissatisfaction, Drive for Thinness, Bulimia. Demographic and Clinical Information: - Age - Sex - Tanner stage (scale of physical development in children,	Hierarchical multiple regression used to identify the best predictors of EDI subscale scores, BMI and glycaemic control. - Significant gender-by-BMI interaction (p = 0.00) - BMI significant predictor for males (p <0.03) and females (p <0.0001) - BMI is a less powerful predictor for males (r^2 = 0.103) than females (r^2 = 0.271) Age by gender interaction for Bulimia subscale on EDI. - Female subjects had a higher Bulimia

[23] Eating Disorders Inventory (EDI): 64-item self-report questionnaire used to assess the presence of eating disorders anorexia nervosa and bulimia nervosa.

	Other *n* = (10%)	adolescents and adults) - Height - Weight - Duration of Disease - HbA1c (glycated haemoglobin)	subscale scores and ale subjects at younger ages. Bulimia subscales scores for female subjects peaked at 13-14 years. Bulimia subscale scores for males increased after 15 years. - Only seven subjects in the total sample scored in the clinically significant range on the Bulimia subscale (score ≥ 5). All seven of these subjects were female and size of these subjects were aged 13-14 years. Predictors of Drive for Thinness - Significant gender by body dissatisfaction interaction (p = 0.01) - Body dissatisfaction more powerful predictor in female (r^2 = 0.484, p < 0.0001) than males (r^2 = 0.185, p < 0.000) Predictors of glycemic control

					- Best prediction model included duration of disease (*p*= 0.01), scoring above clinical cut-off on Bulimia scale (*p*= 0.04) and obesity (*p*= 0.09) Additionally: - When compared with a normative sample. Male adolescents with type one diabetes reported significantly fewer symptoms of bulimia - Female adolescents with type one diabetes reported significantly less body dissatisfaction
Peterson et al., 2018 America QR= 89%	Study hypothesised that known risk factors for bulimic symptoms including body dissatisfaction, dietary restraint, and depression would account for significant variance in bulimic symptoms. Additionally, that after controlling for the effects of psychosocial risk factors, glycemic control and uncontrollable hunger would account for unique variance in bulimic	Quantitative Cross-Sectional Purposive Sampling	*N*= 43 American youth Age: 10-17 Mean age: 12.9 years (SD 1.8) Mean duration of diabetes: 4.3 years (SD 3.5) Female *n*= (54%)	Questionnaires Measured Used: Eating Disorder Inventory-III (EDI-III; Garner, 2004) Youth Risk Behavior Survey[24] (YRBS; Kolbe et al., 1993)	Bivariate correlations were computed between risk variables, and risk variables and bulimic symptoms. - Bulimic symptoms significantly correlated with DTSS Uncontrollable Hunger sale (*r*= .32, *p*= <.05) - Bulimic symptoms significantly correlated with BMI score

[24] Youth Risk Behaviour Survey (YRBS): youth-based survey monitoring risks that contribute to the leading causes of death and disability and social problems among youth and young adults.

κ = 1.000	symptoms in this sample of youth with type one diabetes.	Male *n*= (46) Ethnicity: Caucasian *n*= (75%) African American *n*= (22%) Other *n*= (3%)	Children Depression Inventory (CDI; Kovacs, 1992) Diabetes Treatment and Satiety Scale[25] (DTSS; Young-Hyman & Davis, 2010) Demographic and Clinical Information: - Age - Gender - Composition of family - Child medical history - HbA1c - BMI	(*r*= .32, *p*= <.05) - Bulimic symptoms significantly correlated with body image dissatisfaction (*r*= .32, *p*= <.05) - Bulimic symptoms significantly associated with depressive symptoms (*r*= .32, *p*= <.05) -HbA1c significantly associated with higher body image dissatisfaction (*r*= .32, *p*= <.05) -Body image dissatisfaction significantly associated with depressive symptoms (*r*= .71, *p*= <.01)	
				Hierarchical Multiple Regression utilised to test the effects of disruption in hunger and satiety on bulimic symptoms when controlling for psychosocial risk factors (body image dissatisfaction, dietary restraint and depressive symptoms) - In the model using all youth with HbA1c data	

[25] Diabetes Treatment and Satiety Scale (DTSS): 20-item measure used to assess hunger satiety and fullness in the context of food intake, insulin regimen and blood glucose.

(total r^2 = 79%, $p < .01$) in the second step of the model, there were main effects depression ($\beta = .36$, $p < .05$) and DTSS uncontrollable hunger ($\beta = .27$, $p < .05$). There were no main effects of BMI score, body image dissatisfaction, dietary restraint, length of illness, or A1c.

- No significant quadratic effect of BMI on bulimic symptoms ($\beta = .11$, $p = .64$).
- Third step of the model, there was a significant two-way interaction, depression DTSS uncontrollable hunger ($\beta = .42$, $p < .01$), that contributed significant unique variance to bulimia scores.
- Examining the simple slopes revealed that a combination of high depression scores and high DTSS uncontrollable hunger scores was associated with the most bulimic symptoms

					(β = - 1.82, *p* < .01) One-way ANOVA found: - Female participants endorsed significantly higher sores on body image dissatisfaction compared to males (*t*= 2.19, *p*= <.05)
Schwartz et al., 2002 American QR= 83% *κ* = .880	An empirical investigation to identify and better understand the conditions under which personal control may contribute to the development of disordered eating behaviours and poor metabolic control in female adolescents with Type one diabetes	Quantitative Cross-Sectional Purposive Sampling	*N*=45 American Youth Age: 12-18 Mean age: 14.4 years (SD 1.7) Mean age at diabetes diagnosis: 9 years (SD 2.8) Female *n*= (100%) Ethnicity: Caucasian *n*= (70%)	Questionnaires Measures Used: Eating Disorder Examination Questionnaire[26] (EDE-Q; Fairburn & Copper, 1993) Shapiro Control Inventory[27] (SCI; Shapiro et al., 1993) Demographic & Clinical information: - HbA1c - Age	Correlations between independent and dependent variables were examined. - EDE-Q scores were not corelated with HbA1c (*r*= -0.05, *p*= 0.73) - Lower sense of control was associated with more ED symptoms (*r*= -0.56, *p* < 0.001) - Lower sense of control over ones' body was associated with more ED symptoms (*r*= -0.62, *p* < 0.001)

[26] Eating Disorder Examination Questionnaire (EDE-Q): 38item self-report measure of the specific psychopathology of eating disorders based on four subscales.
[27] Shapiro Control Inventory (SCI): 187-item, 9-scale self-report questionnaire that measures aspects of control and overall sense of control.

		- Menstruation status - Age of menarche (first occurrence of menstruation)	- Lower overall sense of control associated with poorer metabolic control when adolescents had been diagnosed <3 years from puberty (r= -0.69, p < 0.001) - Weaker sense of control over one's body was associated with poorer metabolic control when adolescents had been diagnosed <3 years from puberty (r= -0.66, p < 0.01) Multiple linear hierarchical regression was used to examine moderator models. - Whilst desire for control did not predict ED symptoms or metabolic control. There was a trend for pubertal status to moderate the relationship between desire for control and ED symptoms (p= 0.06) - None of the above findings were confounded by demographic variables.

Sellami et al., 2020 Tunisia QR= 83% *κ* = .870	Purpose of the study was to estimate the prevalence of EDs disorders in a group of type one diabetic adolescents aged between 11-18 years old and to identify risk factors associated with this disorder.	Quantitative Cross-Sectional, population-based study Purposive Sampling	*N*=102 Tunisian youth Age: 11-18 Mean Age: 17.1 (SD 1.5) Female *n*= (51%) Male *n*= (49%) Underweight *n*= (3%) Normal weight *n*= (80%) Overweight *n*= (9%) Obese *n*= (7%)	Questionnaires & Structured Interview Measures Used: Arabic version of Medication Adherence Questionnaire[28] (MAQR; Morisky et al. 1986) Diabetes Quality of Life for Youth Scale[29] (DQOLY-SF; Ingersoll & Marrero, 1991) Eating Attitudes Test- 40[30] (EAT-40; Garner & Garfinkel, 1979) Bulimic Investigatory Test Edinburgh[31] (BITE; Henderson & Freeman, 1987) Diagnostic Interview:	Therapeutic adherence low in 29% of cases. Insulin omission present in 8% of patients (11.5% female, 4% male, *p*= 0.2) Univariate analysis showed that the main risk factors associated with EDs among adolescents with Type 1 diabetes were: - female sex (*p*= 0.006) - abdominal obesity (*p*= 0.005) - hypercholesterolemia (*p*= 0.04) - impaired quality of life (*p*= 0.005) Multivariate analysis revealed the independent risk factors associated with ED among adolescents with type one diabetes: - Female sex was significantly associated with this disorder (adjusted OR= 3.5 and 95% CI = 1.5-8.6). - Abdominal obesity was also significantly

[28] Medication Adherence Questionnaire (MAQR): Four-item self-report questionnaire to identify barriers to medication adherence.
[29] Diabetes Quality of Life for Youth Scale (DQOLY-SF): 38-item self-report measure to assess perceptions of the impact of an intensified diabetes regimen on general satisfaction with life and on concerns over social and vocational issues related to their diabetes.
[30] Eating Attitudes Test- 40 (EAT-40): 40-item psychological self-report assessment measure of symptoms and concerns characteristic of an eating disorder.
[31] Bulimic Investigatory Test Edinburgh (BITE): 33-item self-report questionnaire to assess bulimic behaviours and identify individuals with symptoms of bulimia or binge eating disorder.

				Mini International Neuropsychiatric Interview M.I.N.I M.I.N.I Mental Anorexia and M.I.N.I Bulimia[32] (Sheehan et al., 1998) Demographic & Clinical Information: - Sociodemographic status - Abdominal obesity - BMI (classified as underweight (UW), normal weight (NW), overweight (OW) and obese (O) - HbA1c - Lipids & Thyroid tests	associated with eating disorders (adjusted OR= 5.6 and 95% CI = 1.5-20.4). - Risk of developing eating disorders was higher among patients with impaired quality of life specifically anxiety about diabetes increased significantly the risk of developing eating disorders. - No significant association between having an eating disorder and age, BMI, diabetes duration, age at diabetes diagnosis, HbA1c, diabetes complications. Medication adherence and total cholesterol.
Sien et al., 2020	Objective of the study was to identify the causative factors of eating problems from qualitative data, among adolescents with type one diabetes mellitus in Malaysia.	Qualitative Survey	*N*=15 Malaysian youth	Interview Measures Used:	Thematic Analysis revealed five themes identified to cause eating problems: *Pressure*

[32] Mini International Neuropsychiatric Interview M.I.N.I- M.I.N.I Mental Anorexia and M.I.N.I Bulimia: 15-minute structured diagnostic interview to identify specific types of eating disorders according to the DSM-IV.

Malaysia QR= 74% κ = 1.000		Thematic Analysis Convenience Sampling	Age: 10-18 Participants by group age: 10-12 years *n*= (7%) 13-15 years *n*= (67%) 16-18 years *n*= (27%) Female *n*= (73%) Male *n*= (27%) Race: Malay *n*= (47%) Chinese *n*= (27%) Indian *n*= (27%)	Semi-structured interview, questions based on participants' responses to Diabetes Eating Problem Survey Revised (DEPS-R; Markowitz et al., 2010). Participants who scored more than 20 points were invited to take part in the interview.	- Stress from school life, Self-induced pressure, - Peer pressure - Pressure from family. *Physiological factor* - Tiredness - Loss of hunger *Psychological factor* - Body image *Patient's low compliance to insulin intake and food control* - Feelings of satiety and omitting insulin. *Fear* - Fear of weight gain and being judged.
Svensson et al.,	The study investigated eating behaviour in adolescent males with type one diabetes and compared	Quantitative	*N*=109	Questionnaires & Interview	Individuals lacking two or more items in a subscale of EDI-C were not included in analysis of

2003 Sweden QR= 67% *κ* = 1.000	it with that in age-matched health male controls.	Case Control study Control Sampling/Case-base sampling	*N*= 139 (controls) Swedish Youth Age: 14-18 Mean age: 16 years (SD 1) Male *n*= (100%) Two parent household: Type one diabetes patients: *n*= (61%) Controls: *n*= (55%)	Measures Used: Eating Disorder Inventory for Children[33] (EDI-C; Garner & Olmstead, 1983) + added questions regarding insulin Semi-Structured interview for those scoring above the cut off rate of 14 on the Drive for Thinness subscale of the EDI-C-Rating of Anorexia and Bulimia adjusted for teenagers[34] (RAB-T; Clinton & Norring, 1999) Demographnic and Clinical Information: - Age - Weight - Height - BMI - Living conditions - Duration of diabetes - Daily insulin dose - HbA1c (glycated haemoglobin)	the subscale and so subscale sample sizes vary. Non-parametric test- Mann-Whitney *U*-test. - Adolescent males with type one diabetes showed significantly higher scores on Drive for Thinness subscale in EDI-C compared with control subjects (*p*= 0.002). Finding consistent with hypothesis that the disease-specific focus on food and eating pattern may contribute to disturbed eating in this age group. - On the bulimia subscale the control group had significantly higher scores than the type one diabetes group (*p*= 0.01). - Findings of significantly higher scores on Drive for Thinness subscale among patients compared with controls may indicate

[33] Eating Disorder Inventory for Children (EDI-C): 91-item self-report questionnaire for children and adolescents used to characterise differences in the symptoms of eating disorders.
[34] Rating of Anorexia and Bulimia adjusted for teenagers (RAB-T): Semi-structed interview to assess eating disorder symptoms and related psychopathology.

					a higher risk for developing a disordered eating in the future. - 21 participants reported forgetting insulin at least twice a month and they had a higher HbA1c than those who had not forgotten (*p*= 0.045) - Five participants took part in the interview- none met the diagnostic criteria for an ED - Males with type one diabetes not living with both biological parents tended to have a higher HbA1c (*p*= 0.072) - Higher education of father associated with lower HbA1c (*p*= 0.015)
Troncone et al., 2020 Italian QR= 89%	The study sought to address the following questions: (1) Are there differences in body image problems between adolescents with type one diabetes and without type one diabetes	Quantitative Cross-Sectional	*N*=183 *N*= 183 (controls) Italian Youth Age: 13-18 Mean age: 15.3 years (SD 1.4)	Questionnaires Measures Used: Diabetes Eating Problems Survey revised (DEPS-R; Markowitz et al., 2010).	Chi-square testing used to test frequencies between groups and Students *t*-tests to compare means of continuous variables between groups. - Compared to control participants adolescents with type one diabetes had higher BMI (*p*= 0.013)

κ = 1.000	(2) In adolescents with type one diabetes and without type one diabetes is there a relationship between body image problems and DEBs.	Control Sampling	Female *n*= (54%) Male *n*= (46%)	Eating Disorder Inventory 3 Referral Form[35] (EDI-3RF; Giannini & Conti, 2008) Sociocultural Attitudes Towards Appearance Questionnaire -4[36] (SATAQ-4; Schaefer et al., 2015) Barratt Simplified Measure of Social Status[37] (BSMSS; Barratt, 2006) Demographic & Clinical information: - Age - Sex - HbA1c (glycated haemoglobin) - Duration of illness - BMI - Socioeconomic Status (SES)	- Females especially had a higher BMI (p< 0.0001) - Compared to controls adolescents with type one diabetes had a lower SES (p< 0.0001) - In participants with type one diabetes females reported higher BMI values than males (p= 0.0001) - In the control group males had a higher BMI than females (p= 0.0001) - Participants with type one diabetes reported higher scores than controls in all EDI-3RF subscales- total (p< 0.0001) - SES negatively associated with DEPS-R score in males - Girls with type one diabetes more frequently showed DEB than boys (p= 0.006)

[35] Eating Disorder Inventory 3 Referral Form (EDI-3RF): 25-item abbreviated version of the EDI-3, self-report questionnaire intended to assess the presence of at-risk symptoms for developing disordered eating behaviours.
[36] Sociocultural Attitudes Towards Appearance Questionnaire -4 (SATAQ-4): 31/28-item gender specific self-report measure assessing the internalisation of appearance ideals.
[37] Barratt Simplified Measure of Social Status (BSMSS): self-report questionnaire used to measure of socio-economic status, administered to adults 18+ or parents of children aged 5-17.

- Internalising a thin or low body fat score (as indicated by SATAQ-4R) significantly associated with a Drive for Thinness in males (p= 0.001) and females
- (p= 0.001)

Hierarchical multiple regression analyses were conducted to evaluate the relationship between DEB and body image problems. DEPS-R scores and Drive for thinness and Bulimia EDI-3RF scores were dependent variables

- Step One- Age and SES, did not contribute to DEB ($p > 0.05$). SES values found to be negatively associated with DEPS-R scores in male participants.
- Step Two- Step one and BMI, illness duration, HbA1c significantly increased DEPS-R score in both genders with type one diabetes
- (males $r^2 = 0.123$, p= 0.001, females r^2= 0.111, p= 0.009)
- Step Three- Steps one and two and SATAQ-4R scores increased DEPS-R scores in both

genders with type one diabetes (males r^2= 0.348, p< 0.001, females r^2= 0.299, p< 0.001)

DEB as Drive for Thinness (EDI-3RF Drive for Thinness score)

- Step one- Age and SES- not significantly associated with DEB in males and females with type one diabetes (p > 0.05)
- Step two- Step one and duration of illness, BMI, HbA1c- significantly increased Drive for Thinness score in males and females with type one diabetes (males r^2= 0.139, p= 0.025, females r^2= 0.138, p= 0.008)
- Step three- Steps one and two and SATAQ-4R scores significantly increase Drive for Thinness scores in males and females with type one diabetes (males r^2= 0.296, p< 0.001, females r^2= 0.364, p= 0.000)

DEB as Bulimia (EDI-3RF Bulimia Score)

- Step One- Age and SES, did not contribute to DEB ($p > 0.05$). SES values found to be negatively associated with DEPS-R scores in male participants.
- Step Two- Step one and BMI, illness duration, HbA1c significantly increased Bulimia scores in females with type one diabetes ($r^2 = 0.074$, $p = 0.047$)
- Step Three- Steps one and two and SATAQ-4R scores significantly increased Bulimia scores in females with type one diabetes (females $r^2 = 0.463$, $p = 0.00$)

Pressure from Significant Others

($p = 0.025$) and the Media ($p = 0.022$) significantly associated with bulimia scores in females with type one diabetes

					BMI and body image problems contributed to a significant increase in DEB risk in both male and female adolescents with type one diabetes BMI ($\beta < 0.426$ $p < 0.05$). Body image ($\beta < 0.572$ $p < 0.05$). BMI was significantly associated with bulimia scores in female adolescents ($p = 0.013$) BMI was significantly associated with Drive for Thinness scores in male ($p = 0.004$) and female ($p = 0.000$) adolescents. None of the variables analysed were found to significantly predict male bulimic symptoms ($\beta < 0.296$ $p > 0.05$).
Tse et al., 2012 American	Purpose of study is to expand current knowledge about DEBs in adolescents with type one diabetes by examining the relationship of DEBs with dietary intake and attitudes towards healthful eating.	Quantitative Cross-Sectional Purposive Sampling	*N*=151 American Youth Age: 13-18	Questionnaires Measure Used: Diabetes Eating Problem Survey (DEPS; Antisdel et al., 2001)	Participants were allocated into two groups based on DEPS score (≥39) Low Risk DE *n= 129* and At risk DE *n*=22 Risk group classification was not significantly associated with

QR= 86% κ = 1.000		Mean age: 15.6 years (SD 1.5) Female *n*= (48%) Male *n*= (52%) Weight Status: Normal/underweight *n*= (64%) Overweight/Obese *n*= (36%)	Dietary Records analysed by Nutrition Data System for Research software Healthy Eating Index- 2005 Scale[38] (HEI-2005; Guenther et al., 2008) Healthful Eating Attitudes Scale[39] (Nansel et al., 2011) Diabetes Management Questionnaire[40] (Mehta et al., 2009) Demographic & Clinical data: - Age - Height - Weight - BMI - HbA1c	age, sex, duration of diabetes or insulin regimen. Analysis of variance showed: - A greater percentage of those in the at-risk (for eating disorders) group were classified as overweight/obese compared with those in the low-risk group (59.1% vs 31.8%, *p*= 0.01). - Diet quality of at-risk group was significantly poorer than the low risk group (HEI score 45.9 vs 53.7, *p*= 0.003). - At risk group had higher percentage of energy intake from total fat (38.2% vs 34.4%, *p*= 0.01), and saturated fat (14.0 vs 12.2, *p*= 0.007) than the low risk group. Total score among at risk group was primarily attributed to lower whole grain intake

[38] Healthy Eating Index-2005 (HEI-2005): Self-report measure of diet quality as described by the key diet-related recommendations of the 2005 Dietary Guidelines.
[39] Healthful Eating Attitudes Scale: A measure of self-efficacy, barriers and positive and negative outcome expectations regarding healthful eating.
[40] Diabetes Management Questionnaire: 20-item self-report measure to assess adherence to diabetes management regimens.

(*p*= 0.01), greater saturated fat intake (*p*= 0.02) and greater intake of solid fats and added sugars (*p*= 0.02)

- Risk for disordered eating was also associated with poorer attitudes towards healthful eating. Compared to low-risk group, the at-risk group reported lower self-efficacy (3.5 vs 3.9, *p*= 0.001) greater barriers (2.4 vs 1.9, *p* <0.001) and greater negative outcome expectations for healthful eating (2.9 vs 2.1, *p* <0.001) as well as lower dietary satisfaction (3.9 vs 2.4, *p*= 0.004).
- Youth at risk for disordered eating showed pooper diabetes management- compared to low risk group the at-risk group reported poorer adherence (*p*< 0.001), monitored their blood glucose less frequently (3.2 vs 4.7 times/day,

					p= 0.002) and had higher HbA1c (10.1% vs 8.6%, *p*< 0.001).
Wilson et al., 2015 United Kingdom QR= *κ* = .870	The study aimed to prove the hypothesis that higher levels of behavioural and cognitive ED symptoms including insulin omission will be associated with female gender, higher BMI, poor glycaemic control, higher levels of parent-child conflict, dysfunctional perfections and lower self-esteem. To also explore whether male and female ED behaviours are different and whether high BMI impacts more on female body dissatisfaction than male body dissatisfaction.	Quantitative Cross-Sectional study Purposive Sampling	*N*=50 English Youth Age: 14-16 Female *n*= (60%) Male *n*= (40%)	Questionnaires & Semi-structured interview Measures Used: Child Eating Disordered Examination[41] (chEDE; Bryant-Waugh et al., 1996)- adapted to include 3 diabetes relevant questions. Rosenberg Self-Esteem Scale[42] (Rosenberg, 1965) Multidimensional Perfectionism Scale[43] (MPS; Frost et al., 1990) Diabetes Family Conflict Scale[44] (Rubin et al., 1989) Strengths and Difficulties Questionnaire[45] (SDQ; Goodman, 1997) Demographic & Clinical Data: - BMI - HbA1c - Weight - Height	Participants split into groups: - No ED & ED - No (eating) restraint & Restraint - No ED behaviour & ED behaviour Parametric analysis showed normal distribution of variables. Relationships between SDQ, self-esteem and glycaemic control were found (*r*> 0.44, *p*< 0.001) - SDQ scores were also correlated with dysfunctional perfectionism and diabetes-related family conflict. (*r*> 0.46, *p* < 0.001) - Self-esteem was associated with diabetes-related family conflict (*r*= -0.53, *p* < 0.001)

[41] Child Eating Disordered Examination (chEDE): 35-item semi-structed interview to measure the frequency and severity of behavioural disturbance to key aspects of eating disorder psychopathology.
[42] Rosenberg Self-Esteem Scale: 10-item questionnaire assessing self-esteem in adults and children over the age of eight.
[43] Multidimensional Perfectionism Scale (MPS): 35-item self-report measure assessing six dimensions of perfectionism.
[44] Diabetes Family Conflict Scale: 19-item self-report questionnaire to assess how much a family argues over key issues in diabetes management.
[45] Strengths and Difficulties Questionnaire (SDQ): 25-item questionnaire used to measure general emotional and behavioural problems.

	- Age - Gender - Ethnicity	Young people reported ED behaviours showed higher levels of eating, shape and weight concerns (Kruskal-Wallis tests, $p < 0.003$). T-tests used to compare the three different groups. - Young people who displayed ED attitudes had higher BMI ($p< .05$), poorer glycemic control ($p< .05$), lower self-esteem ($p< .05$) and increased family conflict ($p< .05$) compared to young people without. - Gender differences in ED attitudes- females had more disordered attitudes. One-way analysis of variance (ANOVA) calculated for female and male participants comparing BMI scores in the three groups - Female ANOVA was significant ($f= 3.47$, $p= 0.046$) - Male ANOVA was not significant ($f= 0.24$, $p= 0.79$)

Wisting et al., 2015 Norwegian QR= 83% κ = 1.000	The study aimed to investigate associations between eating disorder psychopathology and illness perceptions, coping strategies, insulin beliefs, insulin restriction, body mass index, and age in young males and females with T1D. Also aimed to assess the magnitude of the explained variance in eating disorder psychopathology, and to investigate whether the pattern of associations differed by gender.	Quantitative Cross-Sectional Purposive Sampling	*N*= 105 Norwegian Youth Age: 12-20 Mean age: 15.7 (SD 1.8) Mean age at onset of diabetes: 9.6 (SD 3.5) Females *n*= (58%) Males *n*= (42%)	Questionnaires & Semi-structured diagnostic interview Measures Used: Brief Illness Perception Questionnaire[46] (BIPQ; Broadbent et al., 2006) Beliefs about Medicines Questionnaire[47] (BMQ; Horne et al., 1999) Adolescents Coping Orientation for Problem Experiences[48] (A-COPE; Patterson & McCubbin, 1987) Interview: Child Eating Disorder Examination (chEDE; Bryant-Waugh et al., 1996) + separate item for insulin restriction.	Bivariate correlations - Among females chEDE global score was significantly associated with BMI (p <0.5), age (p < .01), insulin restriction due to weight and shape concern (p < .01), the ACOPE total score (p < 0.05), the BIPQ overall score (p < .01) and BMQ subscale insulin concern (p < .01) Multiple regression analysis: Among females the ACOPE total score, BIPQ overall score, BMQ insulin concern, insulin restriction Age and BMI entered into regression equation.

[46] Brief Illness Perception Questionnaire (BIPQ): Nine-item self-report measure of illness perception.
[47] Beliefs about Medicines Questionnaire (BMQ): A measure of beliefs about medicines in general (two, four-item factors) and beliefs about one specific medicine (two, five-item factors).
[48] Adolescents Coping Orientation for Problem Experiences (A-COPE): 54-item self-report questionnaire used to identify coping strategies employed by adolescents.

Demographic & Clinical data:

- HbA1c (glycated haemoglobin)
- Age
- Weight
- Height
- BMI
- Diabetes duration
- Age at onset of diabetes

- Model accounted for 53% of the variance in chEDE global score ($p < .0001$)

Significant variables were:

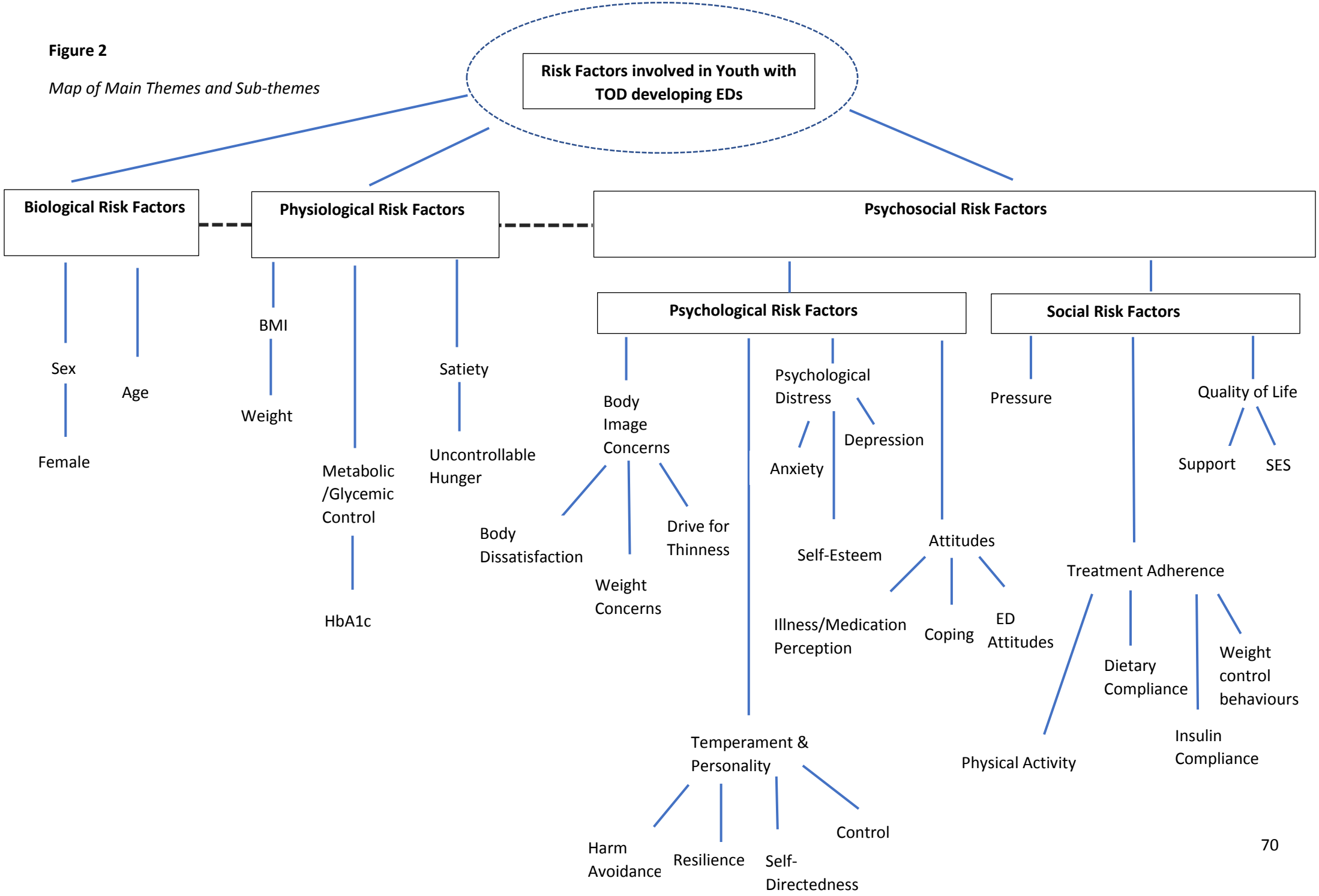
- Age ($\beta = .32$, $p < .01$)
- BIPQ overall score ($\beta = .26$, $p < .05$)
- Insulin restriction due to weight concern ($\beta = .40$, $p < .001$)
- Explained 48% of the variance
- None of the variables significantly associated with ED psychopathology among males.

3.1 Themes from Analysis

A brief overview of the included studies can be found in Appendix G. Following an in-depth analysis of the identified articles, three main themes were generated that identified the different risk factors that may contribute to an individual with TOD developing an ED. These were; Biological Risk Factors, Physiological Risk Factors, and Psychosocial Risk Factors (see Figure 2). Accompanying this, the following narrative will summarise the main findings from the articles that contributed to these categories. It is important to note that whilst there are distinct categories that arise from the data, the different risk factors are often compounded by one another. Appendix H highlights the contribution that each article made to the main themes and sub-themes.

Figure 2

Map of Main Themes and Sub-themes



3.2 Biological Risk Factors

Sex differences

Several of the studies highlighted the gender differences within TOD and their risk for developing eating pathologies (Araia et al., 2020; Cherubini et al., 2018; Gyrlli et al., 2005; Howe et al., 2008; Meltzer et al., 2001; Peterson et al., 2018; Sellami et al., 2020; Troncone et al., 2020; Wilson et al., (2015); Wisting et al., 2015). Overall, these studies reported that young females with TOD were most at risk for developing EDs. In the only all-male study included, Svensson et al. (2003) found that males without TOD had significantly higher scores on the Bulimia subscale of the EDI-C ($p = 0.01$) than males with TOD.

In contrast, Tse et al. (2012), classified youth into an at-risk group for DEB and a low-risk group for DEB and found that risk group classification was not significantly associated with gender. Whilst Araia et al. (2020) did notice gender differences, they also noted that the level of DE risk across genders did not differ when body dissatisfaction was added to their model. However, it is possible that this may be because the magnitude of body dissatisfaction may differ between males and females but not the effect that body dissatisfaction has on DE (Araia et al., 2020). Furthermore, the DEPS/R (Markowitz et al., 2010) may be inaccurate in identifying bulimia symptoms in males as items relating to compensatory behaviours often focus on purging behaviours, whereas males may be more likely to engage in excessive exercise or focus on muscularity (Troncone et al., 2020).

Age

Wisting et al. (2015) reported that age was significantly associated with ED psychopathology amongst females ($p < .01$). Similarly, Meltzer et al. (2001) found that there was an age by gender interaction in predicting bulimia subscale scores ($p = 0.00$) and that female subjects had higher bulimia scores which peaked around age 13/14. Conversely, Tse et al. (2012) found that at-risk for ED group allocation was not significantly associated with age. Similarly, studies by Troncone et al. (2020) and Howe et al. (2008)

found that age did not contribute to DESP score ($p > 0.05$). However, the study by Howe et al. (2008) included individuals aged 11-20 and found that the mean age for those using unhealthy weight control behaviours was significantly higher than those who did not. The discrepancies in studies may be because whilst chronological age is the same across cultures, the period of adolescence most typically associated with the ages indicated within the studies, is transitional (Chen & Farruggia, 2002). Therefore, the risk of an ED could be more closely associated with the period of adolescence rather than a particular age group.

3.3 Physiological Risk Factors

BMI

Several high quality studies found that BMI is a significant predictor of DEB or ED risk in both males and females with TOD (Araia et al., 2020; Cherubini et al., 2018; Gyrilli et al., 2005; Meltzer et al., 2001; Peterson et al., 2018; Troncone et al., 2020; Wilson et al., 2015; Wisting et al., 2015). Wilson et al. (2015) found that young people with TOD who displayed ED attitudes had higher BMIs. Equally, Troncone et al. (2020) found that BMI contributed to significant increase in DEB risk for both male and female adolescents with TOD. Furthermore, the authors reported that BMI values were significantly associated with bulimia scores in adolescent females with TOD ($p = 0.013$) and drive for thinness in male and female adolescents (respectively $p = 0.004$ and $p = 0.000$). Similarly, Meltzer et al. (2001) found that BMI was a significant predictor for body dissatisfaction for males ($p < 0.03$) and a significant and more powerful predictor of body dissatisfaction in females ($p < 0.0001$). In contrast, Howe et al. (2008) and Sellami et al. (2020) did not find any significant interaction between BMI and EDs. However, a contributor to a high BMI is weight and Sellami et al. (2020) noted that abdominal obesity was an independent factor associated with ED and multiplied the risk of developing an ED by 5.6.

Glycaemic control

Metabolic control or glycaemic control was found to be significant in several studies and is a measure of a person's typical level of blood sugar indicated by HbA1c levels. Higher HbA1c levels are typically associated with poorer diabetes control which may be a result of deliberate non-compliance with diabetes treatment. Studies using regression analysis (Araia et al., 2020; Cherubini et al., 2018; Howe et al., 2008), found that a higher HbA1c level contributed significantly to the variance in DEPS-R positive scores (Markowitz et al., 2010). Conversely, divergent results were reported by Sellami et al. (2020), who reported that there was no significant association between HbA1c levels and the presence of an ED. The studies mentioned were all deemed to be high quality. Therefore, considering the differing results, it may be prudent to interpret these findings regarding glycemic control, in conjunction with treatment adherence when considering ED risk in young people with TOD.

Satiety

Peterson et al. (2018) found that bulimic symptoms were significantly correlated with the Diabetes Treatment and Satiety Scale, Uncontrollable Hunger subscale ($p < .05$; DTSS; Young-Hyman & Davis, 2010). Participants in Sien et al's. (2020) qualitative study, highlighted that they struggled with controlling their food intake due to hunger and were more likely to "follow their appetite than think about the consequences" (Sien et al., 2020, p.1313).

The presence of these risk factors highlights an underlying physiological component to TOD that could mean eating is disrupted rather than disordered. The disease process and treatment of TOD may cause disruptions to hunger and satiety, which results in uncontrollable hunger. Howe et al. (2008) reported that young people with TOD at risk for DE had poorer attitudes towards healthy eating and so may be more inclined to binge-eat on unhealthy foods or be less inclined to stick to a diet. As a result, there may be weight gain which leads to a higher BMI and fluctuations in HbA1c levels. Furthermore, a young person may then use insulin omission to regulate their weight, causing elevated HbA1c levels.

3.4 Psychosocial Risk Factors

3.4.1 Psychological

Body Image

Body image concerns were a consistent theme found within studies that explored psychological correlates of EDs amongst youth with TOD (Araia et al., 2020; Howe et al., 2008; Kaminsky & Dewey, 2013; Meltzer et al., 2001; Peterson et al., 2018; Sien et al., 2020; Svensson et al., 2003 Troncone et al., 2020) . Greater body image concerns (body dissatisfaction and/or weight concerns) typically preceded instances of ED (Rosewall et al., 2018). Participants in Sien et al's. (2020) study reflected that wanting to look better by reducing their weight meant that body image was prioritised over diabetes management. For these participants even the fear of gaining weight contributed to eating problems (Sien et al., 2020). Similarly, Svensson et al. (2003) reported that males with TOD showed significantly higher scores on the drive for thinness subscale of the Eating Disorder Inventory for Children (EDI-C; Garner & Olmstead, 1983). Studies suggest that body dissatisfaction is a significant contributor to the risk pathway of ED in young people with TOD irrespective of gender and is linked to the use of DEBs to control weight.

Psychological Distress

A common theme amongst studies exploring psychological correlates of ED was psychological distress. In their study Peterson et al. (2018) found a significant two-way interaction between depression and diabetes- related uncontrollable hunger which contributed to a unique significant variance in bulimic symptoms ($p < .01$). Araia et al. (2020) examined general emotional wellbeing and found that this inversely negatively correlated with DE, suggesting that good emotional wellbeing is a protective factor against DE. Wilson et al. (2015) noted that young people with TOD who displayed ED attitudes had lower self-esteem ($p < .05$). Although, Kaminsky and Dewey (2013) found that higher levels of self-esteem were associated with a higher drive for thinness and greater body dissatisfaction in

adolescents with TOD the authors noted that this finding was contrary to previous research. They proposed that this could be because young people with higher self-esteem may have higher expectations of themselves, which extends to body image (Kaminsky & Dewey, 2013).

Temperament and Personality

Linked to psychological distress is temperament and personality traits. When looking into possible protective factors for DEB risk, Araia et al. (2020) found diabetes-related resilience to be negatively correlated with DE in both males and females ($p < .01$). Additionally, they found, diabetes resilience and emotional wellbeing explained 18% of the variance in DEPS-R scores. Suggesting that good emotional wellbeing and diabetes resilience is protective. Schwartz et al. (2002) examined personal control and found that a lower sense of bodily and overall control was directly related to ED symptoms in female participants with TOD ($p < 0.001$). Interestingly, both were associated significantly with poorer metabolic control when adolescents had been diagnosed less than three years from puberty. Kaminsky and Dewey (2013) found that young people who held the belief that a parent or healthcare provider were in control of their health were more positive about their bodies. Eisenberg et al. (2016) also studied control and examined whether participants were eating healthily for themselves (autonomous motivation) or because it was important to others (controlled motivation). Their study found that controlled motivation was positively correlated with DEB ($p < 0.001$) and this association was made stronger for those with a lower self-efficacy. Grylli et al. (2005) studied temperament and character and reported that harm avoidance (response to adverse stimuli) and self-directedness (identification of self as an autonomous individual) were significant predictor variables in adolescents with sub-threshold or clinical EDs (respectively, $p = .002$, $p = .006$). Of note, is that in this study of 199 adolescents, 11.5% of females and 0% of males met the clinical criteria for an ED and 13.5% of females and 1% of males displayed sub-threshold eating problems (Grylli et al., 2005) further highlighting the gender differences in risk for ED within the TOD population.

Attitudes towards ED and TOD

Attitudes and perceptions towards EDs and TOD were present as another sub-theme, Wilson et al. (2015) examined risk factors in young people with TOD and found that there were factors that distinguished those with ED attitudes from those who did not. Young people who displayed ED attitudes overall had higher BMI scores, poorer glycaemic control (which supports previous findings), lower self-esteem and increased family conflict. Wisting et al. (2015) concluded that in females the chEDE (Bryant-Waugh et al., 1996) global score was significantly associated with perceptions about coping ($p < .05$), perceptions about illness ($p < .01$) and concerns about insulin use ($p < .01$). Additionally, Araia et al. (2020) found that diabetes distress (severity of diabetes-related problems) correlated significantly with DE in female and male participants ($p < .001$).

3.4.2 Social Risk Factors

Pressure

Sien et al. (2020) reported that pressure was one of the main themes present in their study: pressure from peers, family who expressed too much concern and self-induced pressure. Participants reported feeling pressure from their school life, resulting in feelings of stress around keeping up with a busy school life and activities. These stressors often caused issues around food and participants reported; skipping meals, finding it difficult to eat in front of others or feeling under pressure to manage how much they ate in front of others.

Troncone et al. (2020), found that females with TOD reported feeling more pressured by family, but less pressured by the media to improve their appearance by attaining a thin body ideal which may lead to increased body dissatisfaction. For female participants pressure by significant others and the media was significantly associated with bulimia scores. In males with TOD, pressure from significant others was significantly associated with a drive for thinness (Troncone et al., 2020).

Treatment Adherence

Treatment adherence in diabetes is considered very important to prevent adverse health outcomes. Among female participants insulin restriction due to weight and shape concerns was found to be significantly associated with the chEDE (Bryant-Waugh et al., 1996) global score (Wisting et al., 2015. Furthermore, stronger perceptions of insulin concern were associated with an increase in insulin restriction and ED psychopathology (p <.001). Similarly, Cherubini et al. (2018) reported that the probability for a DEPS-R positive score increased by 36% for every insulin injection forgotten or purposefully missed per week. Furthermore, using multiple correspondence analysis they were able to produce a profile of participants who scored positively on the DEPS-R (Markowitz et al., 2010). These participants were more likely to; be female, have significantly higher HbA1c levels, use higher insulin doses, spend significantly less time in engaged in physical activity and have a higher BMI. Conversely, those with a DEPS-R negative score were more likely; to be male, not to restrict insulin and to spend more than two hours in physical activity per week. Sellami et al. (2020) found in their study that low adherence to treatment was observed in 20.6% of participants and insulin omission in 9.3% of participants.

Tse et al. (2012) identified risk groups for DE amongst youth with TOD. Youth considered at risk for DE had poorer diet quality, poor dietary satisfaction, a higher intake of fats, lower self-efficacy for healthy eating, poorer diabetes management, and less frequent glucose monitoring. Howe et al. (2008) found that participants with TOD who perceived themselves as overweight tended to engage in unhealthy weight control behaviours such as fasting, skipping meals and increased smoking, behaviours that contradict positive diabetes management.

Quality of life

Sellami et al. (2020) found that impaired quality of life was an independent factor associated with ED and noted that the most implicated domain in the impairment of quality of life was "parents' involvement". However, it is not clear what type of involvement this pertained to. Wilson et al. (2015) found that participants who displayed ED behaviours had higher instances of diabetes-related family conflict, which could create an environment negatively impacting on quality of life. Cherbuini et al. (2018) found that a DEPS-R positive score was associated with low/medium family profiles of education and low profiles of family occupation, Similarly, Troncone et al. (2020) reported an association between DEBs and lower SES, poorer glycaemic control and duration of illness. When assessing for quality of life as a protective factor, Araia et al., (2020) reported that DE negatively correlated with general quality of life.

3.5 Critique of Studies

Of the 16 studies included, 15 studies employed a quantitative methodology and one study used qualitative methodology (Sien et al., 2020). It is noteworthy that sample sizes varied considerably across the identified studies, from 477 (Araia et al., 2020) to 15 (Sien et al., 2020). This is to be expected when including studies employing different methodologies. However, the findings and generalisability of studies with small sample sizes should be interpreted with caution (Kaminsky & Dewey, 2013; Peterson et al., 2018; Schwartz et al., 2002; Wilson et al., 2015). Furthermore, all but two studies (Eisenberg et al., 2016; Sien et al., 2020) used a cross-sectional study design which limits the generalisability of the findings as causality cannot be examined. Studies noted that prospective longitudinal design studies would be useful for further examining the etiological relationship between identified risk factors for ED amongst young people with TOD (Araia et al., 2020; Cherubini et al., 2018, Peterson et al., 2018 Tse et al., 2012; Wisting et a., 2015). This would better establish a sequence of events, changes over time and would provide further insight into cause and effect relationships.

Six studies used the DEPS(R) as self-report measure of DE behaviour (Araia et al., 2020, Cherubini et al., 2018; Eisenberg et al., 2016; Howe et al., 2008; Troncone et al., 2020; Tse et al., 2012), however the reliability and validity of DEPS had not been determined for children and adolescents until a study done by Wisting et al. (2013). The studies published before 2013 that used the DEPS should be interpreted with caution. Additionally, the DEPS-R include items that are not specific to DEBs but rather attitudes towards diabetes management and weight (Cherubini et al., 2018).

All but one of the studies (Sien et al., 2020) used self-report measures which may yield vague or biased ratings of subjective perceptions of thoughts, feelings and behaviours that participants may or may not fully disclose (Althubaiti, 2016). For example, Svensson et al. (2003) found that three of their participants reported omitting insulin on the EDI-C but denied this during the subsequent interview.

Four studies reported a low response rate, Araia et al. (2020) – 13%; Eisenberg et al. (2016)- 24%; Kaminsky and Dewey, (2013)- 16% (TOD) and 7% (control cases); Wisting et al. (2015). Low response rates can give rise to sampling biases and studies may have under or overestimated effects of risk factors, further limiting generalisability (Evans, 1991).

Finally, although the majority of the studies did well to include both male and female participants unless specifically single sex studies (Schwartz et al., 2002; Svensson et al., 2003), there was still an issue around representation identified within certain studies. Where race or ethnicity was reported the studies ranged from being 70%-91% Caucasian (Eisenberg et al., 2016; Howe et al., 2008; Kaminsky & Dewey, 2013; Meltzer et al., 2001; Peterson et al., 2018; Schwartz et al., 2002). Sien et al. (2020) noted that their use of non-representative convenience sampling meant that their findings were not reflective of the wider population of Malaysia. Controlling for demographic and other selection factors may enhance replicability and generalisability to the wider population.

4.0 Discussion

The present review synthesised current empirical literature and identify the risk factors for young people with TOD for developing EDs. Broadly, the findings suggest that there are a range of risk factors that can be identified which have implications for ED screening in TOD and TOD management.

Results from the analysis indicated that there seem to be identifiable risk factors for young people with TOD for developing ED. These can be understood in terms of biological, physiological, psychosocial risk factors, however the interaction between these may be key. The literature highlights that there are often associations between factors that compound risk for EDs. The necessary hyper-vigilance around diet and weight management may leave young people and young females in particular, at risk from body dissatisfaction which subsequently might lead to weight control behaviours that include DEB. Furthermore, the consequences of not managing diet and weight properly, which may or may not be within their control, for example, due to socioeconomic circumstances, may further put a young person's physical health at risk. This could then lead young people to feel pressure to control these aspects even more closely or conversely, relinquish control to others. Additionally, managing a chronic health issue might impair an individual's quality of life, affecting their illness perceptions, treatment adherence and leave them susceptible to mental health difficulties which increases the likelihood of developing an ED.

This review builds on conceptual reviews carried out by Hanlan et al. (2013), Peterson et al. (2014) and Pinhas-Hamiel et al. (2015). The research completed by Hanlan et al. (2013) identified adolescence, gender, higher BMI, Body dissatisfaction (as drive for thinness) and meal structure as risk factors for people with TOD developing EDs. The current review identified risk factors that were in keeping with this research. However, Hanlan et al. (2013) identified meal structure (set mealtimes) as a risk factor, particularly for adolescent girls with TOD, where infrequent family meals were associated with a higher report of disordered eating. This review did not find meal structure to be a risk factor.

This may be related to the scope of the review in that only adolescent data was included, rather than familial or parent data.

Peterson et al. (2014) identified insulin treatment, weight gain, body dissatisfaction, dietary regimen, dietary restraint, depression and hypoglycaemia as risk factors. Hypoglycaemia is where which the blood sugar level is lower than normal and this condition is usually more prevalent in people with insulin dependent diabetes (Morales & Schneider, 2014). Although not identified as a risk factor within this review, hypoglycaemia can lead to episodes of overeating, as it can cause disruption to appetite regulation causing disinhibited eating (Merwin et al., 2014). This review did identify satiety, underpinned by uncontrollable hunger, as a risk factor and hypoglycaemic episodes may be a contributing factor to uncontrollable hunger. Noted in the study by Peterson et al. (2014) is that there is a lack of distinction between actual hypoglycaemic and perceived hypoglycaemic episodes which could create a two-fold effect that may enhance the risk of binge-eating. Similarly, Pinhas-Haimel et al. (2015) also recognised hypoglycaemia as a clinical sign of an ED amongst adolescents with TOD. In addition to this the authors identified recurrent diabetic ketoacidosis (DKA) as clinical sign of an ED, which is a known complication of insulin omission. Overall, the evidence suggests that this review is in line with previous research findings.

4.1 Study Limitations

This review is not without limitations, the main being the inclusion of *only* young people with TOD. Due to the inclusion criteria, studies which included parents' data were excluded. This potentially excluded factors that may have pertained to social risk factors. Maharaj et al. (2003) found that maternal weight and shape concerns and impaired mother-daughter relationships significantly predicted eating disturbances in females with TOD. Mellin et al. (2004) observed that families of females with DE were more likely to have a parent who made negative comments about weight and eating or engaged in behaviours to lose weight. Additionally, Caccavale et al. (2015) reported that

family eating and diabetes management variables accounted for 20.8% of the variance in DEB. The inclusion of parent data would have aided further identification of risk factors that are systemic in nature. Furthermore, this may have accounted for some of the variance in findings compared to previous conceptual reviews.

In addition, a more inclusive age range may have facilitated comparison of risk factors development across the lifespan. It is recognised that puberty and adolescence is a particularly vulnerable period of time whereby an individual (mainly females) may be more at risk for developing EDs (Klump, 2013). Traditional theories posit that there are psychosocial effects to the physical changes associated with puberty alongside biological and genetic factors that have been recognised to significantly contribute to ED risk (Klump, 2013). Including a range of ages could give insight into the stability of risk factors over time and support the grouping of risk factors by concern for particular age groups.

Finally, although a narrative synthesis was considered to be the most appropriate approach to conduct this review there may be potential biases in the review process. Although every attempt was made to ensure the robustness of this review, narrative synthesis has been noted to lack clarity with regards to its methodology (Dixon-Woods et al., 2005). Subsequently, it is difficult to describe results without an element of selectivity or bias in terms of emphasising certain findings over others (Ryan, 2013).

4.2 Future Research Directions

The current evidence base for EDs is expansive and continues to grow. EDs within TOD have been widely recognised as a phenomenon that requires further exploration to guide treatment and interventions. Whilst identifying risk factors for the development of EDs in TOD is a step towards that aim, longitudinal research is needed to further explore the relationship between EDs and clinical and psychological variables.

ED within the TOD population is a complex issue due to the specific aspects of diabetes management that require a focus and attention to diet and weight. This may also explain why standard screening measures may not be as sensitive to the complexities involved in ED presentations in young people with TOD (Powers et al., 2012). Qualitative studies exploring young people's experiences of diabetes management may be helpful and allow for more insight into the cognitions and perceptions of young people around diabetes specific eating problems. Greater exploration of body dissatisfaction using qualitative measures may provide more insight into how young people navigate this chronic illness alongside increased psychosocial pressure concerning weight and body-shape. Whilst the current research has highlighted that females with TOD are more likely to develop EDs it is important to continue to include males and the male experience within research.

Finally, research should continue to explore interventions within this population. As mentioned previously, there are poor health outcomes associated with comorbid TOD and ED. Research into the efficacy of current interventions may contribute to understanding where treatment may be ineffective and whether this might correspond to the risk factors identified. In addition to this, it might be useful to research help-seeking behaviours within this population to understand their concerns about their health needs, what they might consider problematic and why or when they might approach healthcare professionals for support.

4.3 Clinical Implications

The findings of this review have several clinical implications for working with young people with TOD. There are clear Biopsychosocial factors underpinning the risk of developing an ED within a TOD population. According to the Juvenile Diabetes Research Foundation (JDRF; 2018) the recommendation for young people with TOD is to see a clinician between every four to six months to monitor, height, weight and sugar levels. The implications of this review suggest that screening for EDs as routine at around the age of adolescence, especially in female patients, may aid with detection

of sub-threshold and clinical EDs. It is important to note that although the current review suggests that female patients may be more at risk for developing an ED, the sex difference could be due to how EDs present within males. Men may be more inclined to present with a focus on muscularity than typical ED symptomology (Lavender et al., 2017) and should be screened as routine, although, differential treatment approaches may be indicated through this screening.

Elevated HbA1c levels as detected through routine screening should be queried as an indicator of an ED in the absence of a medical explanation for the elevated values (Geobel-Fabbri, 2008). Additionally, it may be pertinent to adjust the medical regimen of young people with TOD if it is indicated that they are suffering from treatment-related effects on hunger. There is evidence to suggest that a less rigid and more flexible approach to dietary regimen is warranted in the TOD population (Dyson et al., 2011). A more flexible approach to eating and diet might mitigate the effects of dichotomous thinking which can lead to rigid dietary restraint (Palascha et al., 2015). A rigid approach to diet may impede an individual's ability to maintain a healthy weight, leading to a higher BMI and increased use of DEBs (Stewart et al., 2002). Thus, controlling for treatment effects and diabetes related distress may reduce the risk for ED symptomology in this population.

The attention to body weight, shape and size inherent to diabetes management may contribute to body image dissatisfaction and research has indicated that a high percentage of people with a high BMI as a result of diabetes experience stigma (Liu et al., 2017). This stigma in turn may negatively impact the way in which the disease is managed as weight satisfaction and weight perception is associated with eating pathology, unhealthy weight control behaviours and body image concerns (Howe et al., 2008; Durso et al., 2016). Routine psychoeducation, Cognitive Behavioural Therapy (CBT) based interventions or counselling about healthful eating behaviours and increased physical activity may decrease the risk of these occurring. Body image concerns can have a deep impact on a person's mental state (Bornioli et al., 2020). Therefore, it is also important for clinicians to screen young people with TOD on personality and psychological distress measures. Identifying personality traits, which may

be accompanied by depression and anxiety (Kleifield et al., 1994) can inform specialist psychoeducation programmes for young people with TOD.

The current study has identified risk factors that are biological, physiological and psychosocial in nature. Due to the variety of identified risk factors, it may be most helpful for clinicians to treat EDs as a potential by-product of TOD. The Five Year Forward View notes that mental and physical health should not be treated as separate (Mental Health Taskforce, 2016). At the time of diagnosis of TOD, it may be helpful to hold an awareness of the possibility that at some point in their TOD journey a young person may develop a sub-threshold or clinical ED. Holding this in mind may facilitate the integration of preventative strategies in diabetes management as standard care. The biopsychosocial model may be a helpful way to frame the difficulties that young people face whilst managing TOD. If young people have an awareness of how TOD is likely to affect their bodies, their relationship to food and their mental health it may prepare them and their families to better manage the disease, associated risk factors and prevent negative illness perceptions.

5.0 Conclusion

There are identifiable risk factors associated with young people with Type One Diabetes for developing eating disorders. The findings from this review indicate that these factors are biopsychosocial in nature and can be used to create a risk profile to support detection and management strategies for EDs in the TOD population. Clinicians working with young people with TOD should hold an awareness of the increased likelihood of this population developing an ED and pay attention to dietary regimen, body image concerns and negative illness perceptions as the focus of preventative interventions.

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Chapter Two

That Label Isn't For Us: A Grounded Theory study of how Young Black British Women Conceptualise Eating Disorders and Disordered Eating

This paper will be adapted for submission to the Journal of Cross-Cultural Psychology (see Appendix I for author guidelines)

Overall Chapter Word Count (excluding abstracts, tables, figures, references and appendices): 8,398

Abstract

Within the United Kingdom an estimated 1.6 million people are directly affected by Eating Disorders (ED) and this is considered an underestimation given that there are eating pathologies that do not meet the diagnostic criteria for EDs, referred to as Disordered Eating (DE). Symptoms of an ED can vary across the diagnosis, but core symptoms include, a constant worry about weight and body shape. Additionally, issues with self-esteem, self-worth and a rigid approach to eating may be present. Much of the ED literature available has been conceptualised from a Eurocentric framework. This is problematic when attempting to understand, identify and treat EDs and DE in ethnic minority groups. This research aimed to gain a better understanding of how young Black British women conceptualise the notions of ED and DE. Using a Constructivist Grounded Theory approach, interviews were conducted with 12 Black British women aged between 18-25 to present a novel theoretical model of how EDs and DE can be understood. Analysis of the findings suggested that these Black British women understand EDs to be a complex phenomenon of which they have a cognitive awareness of, but no personal connection to. Conversely, DE as a concept provides a more accessible framework for Black British women to understand experiences of eating disturbances or distress. Findings from this study have implications in relation to prevention, identification and treatment of eating disturbances in Black women. Future studies should aim to recruit a more diverse sample and should consider exploring the experiences of Black women who have been diagnosed with a clinical ED.

1.0 Introduction

1.1 Background

In the United Kingdom (UK) an estimated 1.6 million people are directly affected by Eating Disorders (EDs), a condition with the highest mortality rates among psychiatric disorders (Arcelus et al., 2011). The number of people diagnosed with EDs in the UK has increased by 15% since 2000 but it is assumed that most figures regarding prevalence in the UK are an under-estimation, with some undiagnosed people experiencing symptoms consistent with the diagnostic criteria (Micali, et al., 2013). There are four diagnostic categories of EDs (DSM-5; American Psychiatric Association [APA], 2013). Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED) and Eating Disorder Not Otherwise Specified (EDNOS; APA, 2013). Core symptoms of EDs include; anxiety about weight and body shape, eating very little, inducing vomiting or taking laxatives and changes in mood. Physical symptoms such as feeling cold and dizzy, pains, tingling or numbness in limbs, fluctuations in weight and amenorrhea can accompany EDs (Christian et al., 2020) Although EDs can be found across the lifespan (Brandsma, 2007), statistics show that those aged between 14-25 are most at risk of developing an ED (AnorexiaandBulimiaCare.org, 2016). Eating pathologies that do not meet the diagnostic criterion for ED are referred to as Disordered Eating (DE; Nuemark-Sztainer et al., 2011).

People with DE may not experience all symptoms associated with EDs. However, they may experience similar issues with self-esteem, self-worth, a focus on excessive or rigid exercising, obsessive calorie counting, anxiety around certain foods and a rigid approach to eating (Gottlieb, 2014). These are important aspects to consider, as a core symptom dimension of DE is body image concern (Sundgot-Borgen & Torstveit, 2010). Body dissatisfaction and by extension body image concern is the main predictor for eating pathologies and underpin EDs and DE (Stice et al., 2011). Perceived sociocultural pressure to aspire to an unrealistic body ideal may lead an individual to manipulate their food intake

and these behaviours are often considered normative among certain populations i.e. young women (Pedersen et al., 2018). Consequently, without receiving any intervention, those exhibiting sub-clinical Disordered Eating Behaviours (DEBs) are more at risk of developing a clinical ED (Fairburn & Harrison, 2003).

Despite the increase in prevalence and diagnosis of EDs; Currin et al. (2007) noted that general practitioners (GPs) may not identify EDs when presented with a clear ED symptom profile. Furthermore, less than 4% of GPs report using clinical guidelines to inform intervention and treatment in ED cases (Currin et al., 2007). The National Institute for Health and Care Excellence (NICE) guidelines state that screening tools and Body Mass Index (BMI) should not be the sole methods for determining EDs (NICE; 2017). However, GPs face a number of challenges in the early identification of EDs, particularly the time pressure associated with assessing the needs of complex patients, therefore they are more likely to rely on quick but inadequate assessment tools to make decisions (Surgenor & Maguire, 2013). This may leave some patients who present with concerns unrelated to weight or dietary restriction, at a disadvantage (Flahavan, 2006). Reid et al. (2009) found that GPs are more comfortable in diagnosing an ED if a specialist service is available in their area, suggesting that a lack of information, training and confidence in ED detection and recognition by GPs is a barrier to adequate diagnosis (Flahavan, 2006).

Alongside under-identified people with EDs or DE within the healthcare system, minority ethnic groups are also underserved by healthcare services (Salway et al., 2020). In the United States (US) studies have shown that BED occurs with equal or greater frequency for African American women than White women (Taylor et al., 2007) and Black teenagers are 50% more likely than White teenagers to exhibit bulimic behaviour (Goeree et al., 2011). However, there is very limited data however, on the prevalence of EDs in minority populations in the UK (Solmi et al., 2016). A UK study based in a multi-ethnic inner city, found that the prevalence rate of EDs was broadly the same as other studies

of Western populations and that a third of all BN cases occurred in participants of Black ethnicity (Solmi et al., 2016). Recent NHS data has highlighted that there is a sharp rise in the number of hospital admissions for EDs among Black, Asian and Ethnic Minority (BAME) populations. There has been a 53% increase in hospital admissions among ethnic minorities and the sharpest rise was from individuals of Black African ethnicity with hospital admissions for ED increasing by 216% from 2017-18 to 2019-20 (Guardian Analysis of NHS data, 2021). This is suggestive of failings at crucial stages; early recognition and intervention in minority ethnic groups.

1.2 Previous Literature

The literature has often been inconsistent concerning ethnic differences in eating pathology (Shaw et al., 2004). Grabe and Hyde (2006) stated that African American women report less body dissatisfaction, diet less frequently and have lower rates of DE than White women. However, Pike et al. (2001), reported that Black women with BED experienced equal or more severe BED symptoms in comparison to White women, although they exhibited less body dissatisfaction. Further meta-analyses demonstrated marginal differences between Black and White women in the prevalence rates of DE (Roberts et al., 2006). Additionally, there does not seem to be a clear understanding of the manifestation of ED/DE or risk factors in Black women. For example, a strong ethnic identity amongst African American women was considered a protective factor in reducing the risk of developing EDs (Rubin et al., 2003). This appears to support the notion that Black women are "buffered" against EDs because they do not subscribe to western beauty standards (Perez & Joiner, 2002). However, Musci et al. (2014) argued that Black adolescent females' desire to approximate the White body ideal; drives ED symptoms and BED. Furthermore, Kroon et al. (2013) linked higher levels of acculturative stress in African American women to a wide array of ED symptoms, thus undermining the notion that EDs are a White middle/upper class phenomenon experienced significantly less by African American women (Tyler, 2003).

Additionally, it appears that there is no equal and consistent access to treatment for this marginalised group. People of colour with self-acknowledged eating and weight concerns are significantly less likely than their White counterparts to have been asked by a doctor about ED symptoms (Becker et al., 2003). Gordon et al. (2006) found that when presented with identical case studies illustrating DE symptoms, only 17% of clinicians identified the Black woman's behaviour as problematic compared to 44% for White women. Similarly, in the UK, Waller et al. (2009) found that ethnic minority patients were less likely to be referred to specialist services: a lack of identification of EDs at a primary care level may account for referral in the White population being over-represented by 25% and the Black population underrepresented by approximately 70%. Sala et al. (2013) suggest that this disparity is perpetuated by the stereotype that EDs are a "White" problem, and that EDs and DE symptoms are not as widely recognised by some individuals within ethnic minorities and the healthcare system. This is of concern given that BN and BED are highly prevalent in Black women and teenagers (Taylor et al., 2007).

Theoretical frameworks that underpin the ED diagnostic label are acknowledged to be socially constructed (Bentall & Pilgrim, 1999). The Biopsychosocial perspective assumes that EDs arise from a combination of biological, psychological and social factors (Engel, 1997). The cognitive-interpersonal model of AN is also based on this assumption (Schmidt & Treasure, 2006). This model proposes that the maintenance of AN involves inherited vulnerabilities such as behavioural inflexibility that interplay with the physical consequences of starvation on the brain, alterations to bodily systems and environmental factors such as the response of family and friends. Another model of ED is the Tripartite Influence Model (TIM) based on the sociocultural perspective of ED (Thompson et al., 1999). This sociocultural perspective proposed that exposure to Western ideals for thinness are internalised through pressure from society, family and friends. This ideal then becomes an individual's preferred body preference leading to body dissatisfaction and risk for ED development (Stice et al., 2015). These

models are based on research that has been mainly conceptualised from a Eurocentric framework (Striegel-Moore et al., 2003). Ethnic minorities have been largely marginalised from ED research and literature, which in turn has limited awareness of how these conditions present in these populations (Sim, 2019). Furthermore, it has cultivated the current stereotype of ED presentations being homogenous and almost exclusive to White females (Gordon et al., 2002). Additionally, most measures of ED symptoms and risk factors were developed in predominantly White female samples (Kelly et al., 2012). Symptom presentation in women of colour however, may be distinct from patterns described within the established ED literature (Kuba & Harris, 2001). Ethnic differences in ED or DE cannot be explained by a single factor such as the culturally induced pressure to be thin (Roberts et al., 2006), yet there are few studies that focus on how EDs can be understood in ethnic minorities (Talleyrand, 2010).

1.3 Rationale

Literature in this subject area demonstrates significant limitations in relation to identifying, understanding, and treating ED/DE in ethnic groups. Firstly, whilst studies have investigated ethnic differences in eating pathology, they have not explored how EDs and DEs are *understood* by individuals within different ethnic groups. Kempa and Thomas (2000), proposed that without recognising and understanding cultural values, treatment for EDs and DE cannot be approached. Current treatments for EDs are underpinned by theoretical frameworks where ethnic minorities have been underrepresented, and as a result may not be culturally sensitive (Goode et al., 2018). Providing cultural context for young Black women within healthcare systems will help shape more productive dialogue between women of colour and health care professionals (Cameron et al., 2018). Secondly, most of the literature concerning ethnic minorities has been conducted within US and has variable findings. Studies including African American women may not be applicable to Black women across all western societies. Generalising these findings negates the fact that Black British women are likely to

have very different cultures, experiences, conceptualisation and dialogue compared to their American counterparts, particularly if acculturative stress is a risk factor (Young, 2000). Finally, research has tended to focus on weight, thinness and obesity as drivers when exploring EDs. It has been suggested that there are non-weight related ideals of body image, i.e. hair and skin tone that can contribute to body image dissatisfaction and EDs (Jefferson & Stake, 2009). Moreover, the impact of the historic devaluing of certain bodies in society, systemic racism and the interaction of gender and race creates another layer of context in which to explore EDs within Black women (Awad et al., 2014).

The aim of this research is therefore to gain a better understanding of how young Black British women, conceptualise the notions of Eating Disorders (ED) and Disordered Eating (DE).

2.0 Methods

2.1 Methodology

The chosen epistemological position for this project was interpretivist, which emphasises the meaningful nature of peoples' character and participation in both social and cultural life (Elster, 2007). An interpretivist position acknowledges that the researcher will not be able to obtain value free data, as their own perceptions will guide the process of enquiry (Walsham, 1995).

In keeping with the epistemological position, this research followed a Constructivist Grounded Theory (CGT) approach. Traditional grounded theory is an inductively driven research strategy that proceeds systematically from specific data collection to generate a theory to explain the data (Mills et al., 2006). Whilst adopting the same rigorous analytic method for theory development, CGT reshapes the interaction between researcher and participants and recognises the need for ongoing reflexivity (Charmaz, 2014).

CGT was the preferred approach for this research due to its application to areas of study that are under-defined and its popularity as a method to analyse accounts of those individuals and groups often considered marginalised (Tweed & Charmaz, 2011). CGT allowed for themes, concepts, categories and theory to emerge from the data, creating a richer and more contextualised explanation for the information gathered (Charmaz, 2014). Addtionally, adopting a CGT approach allowed the researcher flexibility to pursue avenues of potential interest.

2.2 Sampling Design

Initially, the research project used a non-probability purposive sampling design. The chosen design meant that the sample was reliant on the subjective judgement of the researcher (Sbaraini et al., 2011). The participants were selected based on the researcher's knowledge of the study and on shared characteristics identified as significant to the proposed research question to increase the homogeneity

of the sample (Morse, 2007). Additionally, it aided with the identification and selection of information rich cases most closely related to the purposes of the research (Palinkas et al., 2013). Following this purposive sampling, a theoretical sampling approach was employed, selecting participants based on the findings of the initial interviews to develop theory and identify emerging concepts and categories through continued data collection (Charmaz, 2014; Strauss & Corbin, 2014; Kwortnik 2003). The process continued to move back and forth between sampling, data collection and analysis to guide where, how and who further data should be collected from (Charmaz, 2014).

With CGT it is difficult to be specific in the number of participants that need to be sampled in order to reach theoretical saturation. Given the time scale of the project the research aimed to collect data for theoretical sufficiency (Dey, 1999) and using the literature as a guide the researcher aimed for between eight and fifteen interviews (Morse 1994; Thomson 2010).

2.3 Inclusion and Exclusion Criteria

Table 6

Inclusion and Exclusion Criteria for Study Sample

Criteria	Inclusion	Exclusion
Ethnicity	Women who identify as: - Black-African - Black-Caribbean - Afro-Caribbean - Any other Black Ethnicity	- Men - Women who are of mixed ethnicity (even if they identify as Black). - Women who identify as an ethnicity other than Black.
Nationality	- Born in the UK - Living in the UK - Able to understand written and spoken English	
Age	- Women aged 18-25	

The inclusion criterion was limited to those who identified as Black-African, Black-Carribbean, Afro-Caribbean or any other Black ethnicity. The decision to exclude those of mixed heritage was given careful consideration, as often they may feel excluded from Black narratives and a collective Black identity (Campion, 2019). Ultimately, it was thought that, mixed heritage and dual identity are unique factors that will warrant separate exploration (Apsinall & Song, 2013). Until recently, ED literature has had a distinctly female focus, which negates gender specific problems (Sweeting et al., 2015). It was thought that the complexities associated with conceptualisation of male EDs would also require separate investigation. The sample focused on those born and residing in the UK to limit as much as possible the number of subcultures that might be present. The additional criteria of understanding written and spoken English is to reduce the likelihood of misinterpretation of language and terminology. The majority of ED literature has focused on women of University age (Eisenberg et al., 2011) therefore, the age range included in this study reflected previous empirical research and current ED statistics.

2.4 Materials

An interview guide was constructed for the data collection (See Appendix J). Areas for discussion were identified by reviewing ED literature. Current research highlighted that exploring non-weight ideals of beauty, body image ideals, culture and acculturation may provide some insight into the conceptualisation of ED pathology in Black women (Pope et al., 2014). The interview guide and format allowed for relevant issues to be discussed and for other relevant topics to arise organically.

2.5 Ethical Considerations

Ethical approval was granted by the Faculty of Health and Life Sciences Ethics Committee at Coventry University (Appendix K). The British Psychological Society's (BPS) Code of Human Research Ethics (2014) was adhered to throughout the research process. Further information regarding ethics considerations can be found in Appendix L.

2.6 Recruitment

Participants were recruited from colleges and universities within the UK. Due to the global Coronavirus pandemic and the resulting closure of colleges and universities, the research project was advertised through two sources; an online learning platform for a University within the West Midlands and through social media platforms Twitter and Instagram using a recruitment poster and an informational poster (See Appendix M & N).

Persons interested in participating contacted the researcher through social media or the researcher's secure email account. The researcher sent out the Participant Information Sheet (Appendix O) and Consent Form (Appendix P) and once the completed consent form was returned, an interview time and platform were agreed upon.

A total of 16 participants were recruited using this format and 12 took part in the research project. Three participants did not return the consent forms and did not respond to follow up emails. One participant withdrew due to health-related reasons. Of the 12 participants, five identified as Black-Caribbean (Jamaican) and 7 as Black African (Nigerian-4, Ghanian-2 & Tanzanian-1). The average age of the participants was 22 years old. The participants were either in higher education ranging from A level to PhD level students (9) or working professionals (3). Finally, seven of the participants had a background in Psychology through study.

2.7 Interview Procedure

One to one semi-structured interviews were conducted with participants. The original protocol was amended to allow for interviews to take place virtually, in adherence with government guidelines. A total of 10 interviews took place through an online video platform, and 2 interviews took place over the telephone. Interviews were audio recorded and transcribed for analysis and ranged in length from 35 minutes to 80 minutes. After the interviews were conducted, participants were sent a debrief form via email (See Appendix Q).

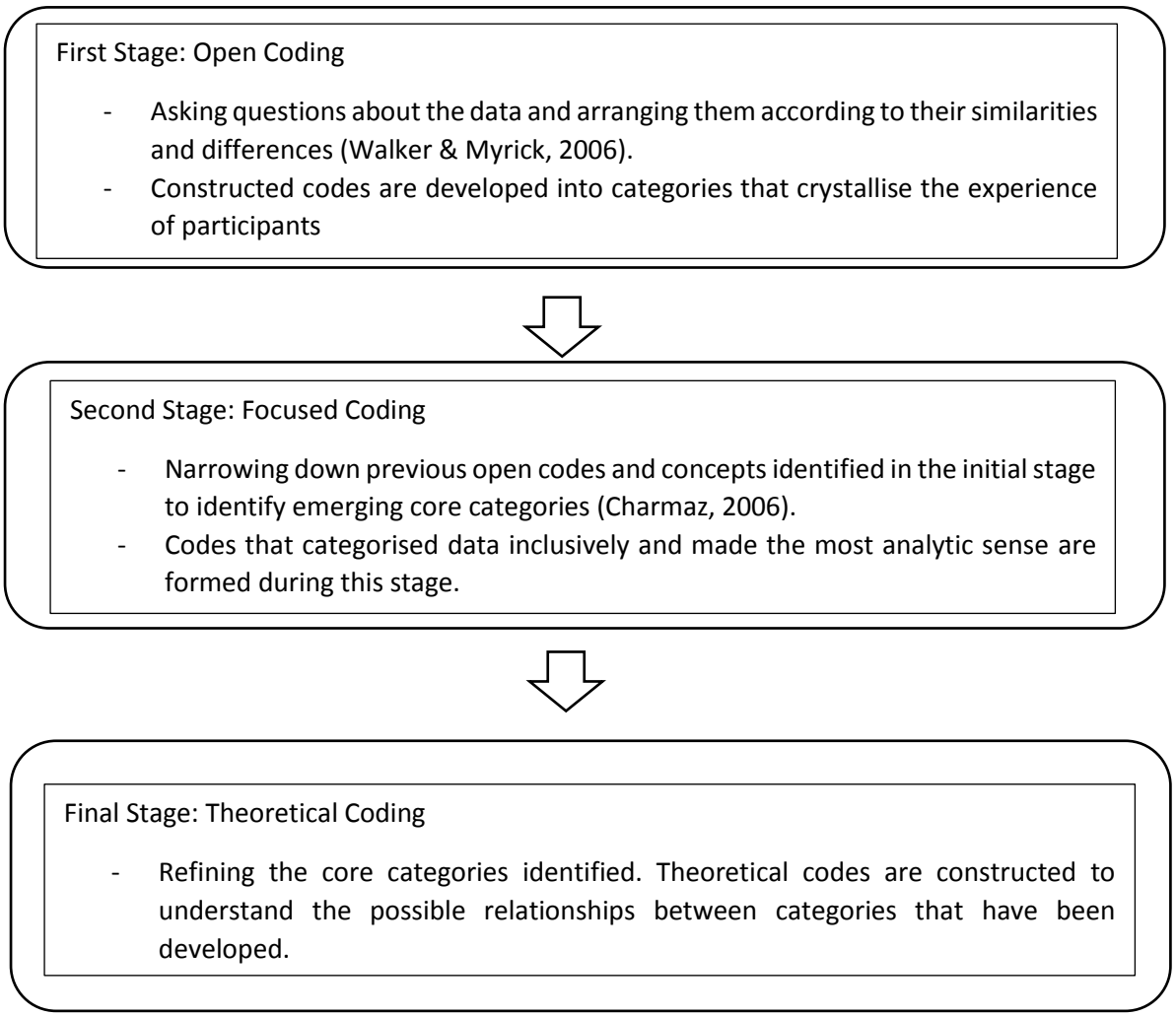
The use of open-ended questions sought to encourage the participants to elaborate (Patton, 2002). As themes and issues emerged from the initial interviews, there was a process of refinement to the interview schedule (See Appendix R) to focus on emerging data to facilitate development of specific categories (Charmaz, 2006). Additionally, the CGT approach afforded the researcher flexibility to interview whilst being able to remain interactive. These interactions allow for a more authentic and in-depth understanding of the co-constructed data, leading to a truly reflective analysis (Mills et al., 2006).

2.8 Methods of Data Analysis

The process of analysis followed guidance given for CGT (Charmaz, 2016). Coding is essential to the development of a grounded theory (Charmaz, 2006). It is through coding that the link between collecting data and its reintegration as a theory is made. Coding in grounded theory refers to the process of labelling significant interview data with a short a precise name (Charmaz, 2006). The process of coding is illustrated in Figure 3. An excerpt of coded transcript can be found in Appendix S.

Figure 3

Stages of Constructivist Grounded Theory Coding



Open Coding was used to generate as many ideas as possible from the early data (Charmaz, 2006). Once the first four interviews were coded, amendments were made to the interview schedule to factor in emerging data[49]. The subsequent interviews included questions that explored the meaning of food culturally, different scenarios involving food consumption, and motivations behind changing eating habits. All interviews were subject to focused coding in order to synthesise larger segments of

[49] The data was coded line by line to fulfil two criteria for GT: fit and relevance (Charmaz, 2006). The research must *fit* the empirical world. The research project has *relevance* when the relationship between implicit processes and structures is visible (Charmaz, 2006).

data. Lastly, theoretical codes were constructed to tell a coherent analytic story from the focused codes (Charmaz, 2006).

2.9 Researcher Reflexivity

Reflexivity refers to the examination of the researchers own beliefs, judgements and practises and how they may have influenced the research process (Finlay, 1998). CGT methodology acknowledges the researcher's experiences and interpretations and offers a space for discussion from a critical perspective (Charmaz, 2006).

As the researcher is a Black British woman, the presence of their assumptions and the influence of these on the analysis was acknowledged. To mitigate these influences, a bracketing interview was conducted. Bracketing interviews, in which the researcher is asked questions from their own interview schedule can amplify the researcher's own reflexive capacity (Rolls & Relf, 2006). The process highlighted to the researcher assumptions they held about who may experience EDs, why EDs may manifest and gave the researcher a chance to reflect on their own relationship to food. Finally, the researcher noted that this was the first time they had a chance to articulate their thoughts on this topic aloud. It felt important to note that intentionally talking about food and eating and unpacking other adjacent topics, had never happened organically.

To manage the researcher's position and own subjectivity throughout the coding process, a simultaneous process of memo writing was also undertaken. The aim of memo writing is to aid reflective thought (Birks et al., 2008). Memo writing involved noting down the researcher's thoughts, feelings and any questions that arose from the analytic process (Charmaz, 2006). Using memos allowed the researcher to monitor findings that had arisen organically from coding the data and their own internal thoughts and assumptions without conflating the two.

A selection of memos written throughout the process can be found in Appendix T. Finally, the researcher kept a reflective journal and received supervision at regular intervals during the research process.

2.9.1 Reliability

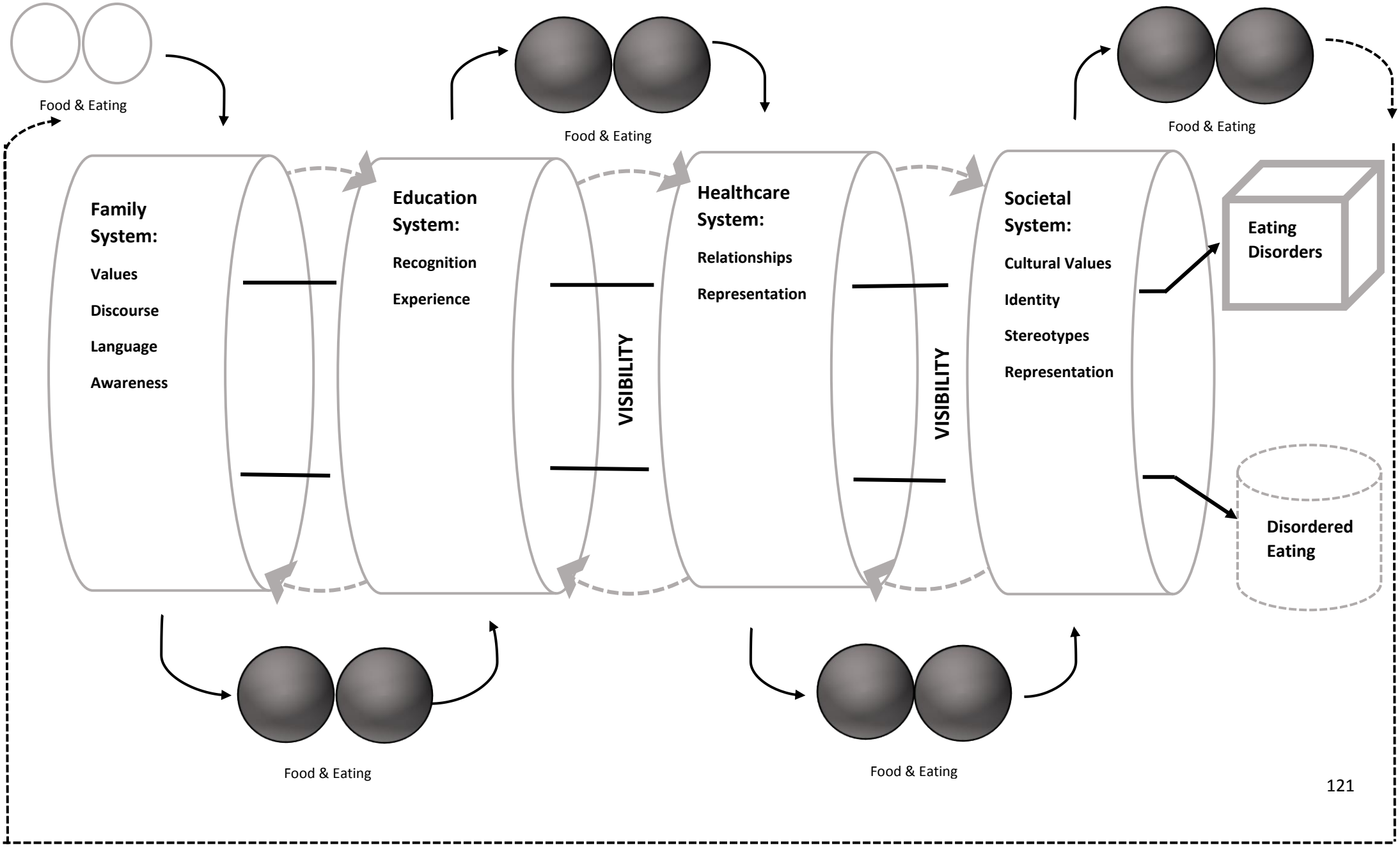
Quality is an important aspect to consider in conducting research. All transcripts were coded and analysed by the researcher. To assess reliability, a section of an interview transcript, chosen at random was separately coded by an independent researcher. The aim was to ensure that any subjective bias would not have a disproportionate influence. The researchers then compared transcripts to consolidate the codes.

3.0 Results

A theoretical relational model was constructed to explain how young Black British women conceptualise ED and DE. Responses from participants contributed to the final categories illustrated in the model, which is shown in Figure 4.

Figure 4

Theoretical model of how young Black British women conceptualise Eating Disorders and Disordered Eating



The model included concepts, categories and processes to describe the conceptualisation of ED and DE from participants' perspectives. From the outset participants identified that food and eating are two concepts intrinsic to their understanding of ED and DE. Participants highlighted four key systems that they encounter and navigate throughout their life, which form part of their context. These were: the *family system*, the *education system,* the *healthcare system* and the *societal system*. Core categories within each system helped to shape and influence the concepts of food and eating and the concepts of ED and DE.

Two parallel processes are described within the model. The first relates to how the concepts of food and eating move through different systems participants encountered. The concepts start as two-dimensional shapes, illustrating a basic understanding of food and eating. As Black women move through the different systems; understanding, meaning and value are attached to food and eating, giving them more depth as concepts, as indicated by the three-dimensional, filled shapes.

The second process is how the concepts of ED and DE are constructed and informed by these same systems. The different shapes of ED and DE represent how the two terms are understood in different ways. The shapes represent how young Black British women's concepts of food and eating can fit (or not) with their conceptualisation of ED. ED is a rigid shape, with a definitive structure that the concepts of food and eating could fit within. At the same time, it might not be the most fitting label for Black women to define their eating pathologies. Whereas the shape and construction of DE might seem more appropriate to hold a young Black British woman's understanding of food and eating and to define their experience of eating pathologies.

The concept of **Visibility** emerges from interactions with the *Education*, *Healthcare* and *Society* systems and influences the development of ED and DE concepts. The young Black British women in this study did not feel that they are visible within society.

3.1 Core Categories

Core categories emerged from the different systems that participants identified. Below is a description of how the **systems**, **concepts** and **core categories** related to each other.

Family System

Participants described how familial **values**, which are influenced by their family of origins culture, play a major role in the development of their individual and community identities, their relationship to food, and their ideas of food and eating. Food and eating are not just an individual experience, they are a community experience and way to communicate with others, *"… definitely a sign of love" [P008; 157]*

Within the family system there was a sense that there is a lot of talking about food and the joy of eating "*…everyone's eating and that is just the pinnacle of conversation" [P012; 91]*, but almost no conversation (**discourse**) about eating habits or disturbances, *"I don't think I've ever been in a space with anyone of a….Black British background where we speak of or recognise eating disorders" [P002; 58].* Interestingly, participants did describe how immediate and extended family members often make remarks about food consumption and weight.

"*…my family in particular are obsessed with weight so I think growing up and even now if my aunts see me, they will inevitably comment on my weight...I can always gauge where I am with my weight based on whether they make a comment..." [P011: 113]*

Participants identified that there may be a problem regarding **language** and there may not be the "*cultural vocabulary"* [P007; 327] to articulate the presence, nuances and ramifications of eating pathologies, *"If you're not eating your being silly." [P008:89]*. The kind of language used around mental health issues is also linked to the lack of cultural vocabulary, "*using the word crazy or idiot…it is seen as a negative connotation" [P005:368].*

The use of **language** and lack of **discourse** may stem from a lack of **awareness** and understanding within the family system about what mental health issues are and subsequently what eating disturbances might look like.

"So, I think if your family…they're not aware of how bad relationships with food can manifest, I think that can leave a lot of Black girls on the wayside of having these patterns that their parents don't pick up as abnormal." [P012; 191].

In this sense, part of the lack of awareness could be due to parents not having the same cultural experience growing up *"But they need to try and transition to understanding how their childhood is different to ours growing up here" [P001; 362].*

Education System

Within this system, there was a **recognition** by participants, that they *felt* different from their peers *"…but I've always known from primary school that my body's a bit...bigger...or thicker than a Caucasian person" [P001; 91].* This bought about an awareness of their identity as Black females and how they might not fit in.

"I feel like during primary school, secondary school and sixth form I had …I would say alternate version of myself. To shield myself from not being seen or accepted…I would say that I'm Black, but just in the movement and the journey of school, sometimes I would be like oh yeah like I'm different, I lowkey [kind of] forgot." [P009; 263]

"I think even when schools talk about mental health and eating disorders and stuff like that, it is always spoken about through a white lens anyway. So, it feels unapplicable to you in some sort of capacity" [P012; 258]

Some participants made the link between **recognition** of this difference and how this could lead to eating disturbances.

"Like if I didn't have that sense of being Black really early on…I could have easily slipped into I just won't eat then, maybe I'll be skinny…" [P007;498]. For this participant, being grounded in a Black identity, through family and wider culture, provided context to her difference and was a protective factor.

Participants also highlighted that this might have been the first time that they would have had any **experience** with the concept of ED, mainly through conversations with peers.

"Yeah, I heard it mostly from like my white friends when they were talking about it…" [P009;53]. "…a girl in my year had an eating disorder…so we kind of had conversations later on…"[P011; 79].

Healthcare System

Participants described a tense **relationship** with healthcare systems and an inherent mistrust of healthcare professionals.

" I think with now more than anything, especially when you are talking in a period of Black Lives Matter …There is always a fear…A lack of trust, a feeling of they don't understand me" [P012; 418]

Participants explained that part of mistrust of the healthcare system is that it is seen as reflecting and perpetuating some of the stereotypes about Black women that are also dominant in the wider society context.

"Black women are portrayed to be like these strong characters like strong twenty-four seven. When that's like not the case at all like we're like allowed to be vulnerable… I feel like some medical professionals have that kind of like stereotype in their head and they kind of erm...project it like onto the Black female patients." [P006; 312].

These stereotypes mean that rather than being seen as multifaceted, Black women have to claim the right to be vulnerable.

"…there's almost an assumption perhaps that a Black person with an eating disorder should be able to sort themselves out because they're in control of it. Whereas a white person erm, is a victim or suffering or vulnerable. [P007; 275]

Ethnic disparities in healthcare among Black and Asian Ethnic Minority women area complex and multi-dimensional phenomenon (Dovidio et al., 2016). Implicit racial bias is thought to negatively influence diagnosis and treatment options when unconscious stereotypes hinder interactions between clinicians and patients (Hoffman et al., 2016).

Participants noted that there is a lack of **representation** when it comes to understanding mental and physical health issues and how they manifest in Black people.

"Black mental health is different to what you see on TV and what you learn about in school. It should be considered important and there are other things that effect it, like racism…" [P010; 339].

"…on TV there's...it's more like white teenagers that are shown and portrayed that way. So... you think that oh maybe this is just an issue that white communities face and people in other communities don't face that and that's why it's not mentioned in our conversations and our own spaces." [P002; 71].

The tense relationships and lack of representation may leave Black women reluctant to confide in healthcare professionals. This then contributes to a negative feedback cycle where Black women may avoid interactions with health services for fear of potential discrimination following perceived poor experience and care (Dovidio et al., 2016).

Societal System

Participants described that the **values** that the wider society holds, namely beauty and body ideal standards *"to have certain facial features…to have a certain skin tone" [P011; 327]* have an impact on Black women's experiences , "*And all of those things I guess 'other' Black women" [P011; 327]* The value placed on body image and size habitually exclude Black women from the narrative of being attractive or desirable. Black women are often not represented within wider society and if they are, "*we're not visualised in a broader sense of Black womanhood" [P012; 140]*. Often there is an emphasis on being acceptable or more palatable, the greater the proximity to whiteness.

"I think... that the Western ideals of beauty...because they're so prominent...it kind of leaves every Black British women susceptible to it [EDs] because that is seen as the baseline in the UK. So, I think from that perspective…it's not really whether they affect you or not...it is just to what extent it affects you..." [P003; 253]

Participants mentioned that the beauty standards and ideals have been subjected to a cultural shift. The trend at the moment is a curvier body ideal that typically Black women are closer to.

"…because now you would say Kylie Jenner is the ideal Western white woman beauty standard, but she obviously co-opts part of Black women's bodies to make herself somewhat more desirable in that space." [P012;286]

Representation was a core category that emerged from the interview data within this system.

"I think the fact that there is no representation. …is very dangerous I would say, because…sometimes it's much easier to go through an experience seeing someone you can relate to in every aspect." [P002; 123].

"I think representation is important because…people are limited to their understandings of what they can be by what is presented before them. So, if you're presented with everyone's white everyone's beautiful, like Disney told us for example who is beautiful in the princesses they chose…" [P007; 648].

There was a link between how the lack representation meant that issues such as EDs in Black women had no reference point, no template *"…anything with eating disorders, you think of White people…" [P006;212]*.

Participants talked about the **stereotypes** that are held about Black women within society and how these can add pressure to Black women *"…I think the stereotypes around vulnerability are a massive erm, factor in changing...outcomes" [P007; 372].*

"I think Black women have the stereotype of having to deal with being excellent and live in excellency and magic and being strong. We may not even want to report our own issues and it may stop us because… that doesn't make me that magical, excellent Black woman that everyone talks about." [P012;386]

The lack of meaningful **representation** and the **stereotypes** held within society may have an impact on how Black women see themselves and their **identity.** Their self-esteem and self-worth may be diminished by the exclusionary nature of society. Therefore, there may be a pressure to fit in with the current "trends" within society to feel validated.

"…it would really damage people's self-esteem… So…you've already understood that people are insulting you because your dark skinned and then on top of that you're trying to achieve this body structure that isn't for you. It's just like another layer of issues." [P009; 343].

"It's inspiring and might boost your self-esteem that there are people like you that exist out in the world who are comfortable and beautiful. Instead of seeing the same thing all the time, where you think well, I'm not like that so I need to change myself." [P010; 269]

This is also exacerbated by social media and the ease and accessibility of content that Black women are exposed to *"… social media is literally like at the tip of your hands. Like it's actually twenty-four seven …it's [body ideals] literally just like in your face automatically." [P006;253]*.

Eating Disorders

Participants were able to give succinct descriptions of how they envision the manifestation and presentation of EDs but described a dissonance between their understanding and the labels applicability to Black women. Many participants described the personification of EDs was a White woman and in that respect the label is very specific

"creating that image of a white female, was probably based primarily on the fact that I didn't see that...or wouldn't think that that would be reflected in my culture as well" [P005; 115].

"I think there is something about the schema or the way things are spoken about or presented or the lack of representation…that image is absent from my mind…" [P007; 264].

"...you read a lot that anorexia tends to be in kind of a highly perfectionist...or might belong to I guess certain areas of society and that image that is portrayed when you think of that, private school, highly educated, dancer, ballerina type is a white person so...maybe subconsciously that's where my brain went, I guess...." [P011; 170]

It was only when participants were asked what an ED might look like for a young Black British woman, were they able to think about the nuances that might be involved in that presentation and particularly, how Black women would be very good at hiding any eating disturbances.

"Being like that desirable image is the only way I can be seen as desirable as a Black woman, so I need to occupy that space and somehow informing our eating choices and what we eat." [P012; 124]

(See Appendix U for additional descriptions)

Disordered Eating

Conversely, the concept of DE appeared to be a more accessible label participants could apply to Black women. There was more opportunity to identify with the concept of DE because it did not already have inherent associations with a particular race, ethnicity or gender.

"There's almost the illusion in my head, despite me knowing it's completely problematic and wrong...that…Black people wouldn't have an eating disorder. It's almost like the difference in the term...you'd say a White person has an eating disorder and I might identify disordered eating in a Black person, but I struggle to look at a Black person and go oh that person has an eating disorder." [P007; 259]

Visibility

The theme of **Visibility** sits within the interactions between systems and influences ED and DE concepts. The participants described how it goes further than not being seen. Participants commented on how there is a very narrow space that Black women can occupy in wider society.

"*…such a narrow scope, and there is so much pressure of like okay well if I don't have that [body ideal] what will it take for anyone to hear me?" [P012;147]*, and if they do not fit within this space; essentially, they do not exist. The nuances of being a Black woman are often absent from the relevant spaces and conversations that effect change.

"So, in that sense I think being forgotten, or not being understood or reflected about means that erm, we're marginalised in a way that is beyond the scope of the everyday person's understanding. It's also about, just not existing in the minds of those who you might need to, in order to get the help that you need" [P007; 349].

4.0 Discussion

The present research study sought to explore how young Black British women conceptualised ED and DE. The study presents a grounded theory model of how young Black British women conceptualise ED and DE, illustrating how different systems interact to contribute to the understanding of these concepts.

Analysis showed that participants do conceptualise both ED and DE but that these young Black British women did not identify with the representation of ED as currently seen in wider society.
Even participants who disclosed that they had struggled with eating disturbances in the past, did not label their difficulties as an ED at the time. Participants were able to relate to the idea of DE as a concept that allowed for more nuanced presentations of eating disturbances. Although, some participants did not distinguish ED and DE as two different concepts with regard to their meaning, they were more likely to ascribe DE, rather than ED as a label to define Black women's eating difficulties.

Awareness, discourse, and representation were cited as some of the most relevant factors that explained why ED did not resonate with the participants as way to understand eating disturbances or distress. The lack of awareness within family structures and communities about what EDs are and how they might present, was linked to how central food is to Black British culture. Food and eating are associated with family, culture, tradition, communion and joy. The idea of food being a source of distress or a means to communicate distress is often not considered or discussed. This is reinforced by the lack of representation within the Healthcare and Societal systems that has meant that their understanding of ED is limited to its specific application to White women. Conversely, participants commented that they had no "template" on which to base the idea of a young Black British woman with an ED. Furthermore, there was a connection between the integral nature of food

in their culture and how that might provide someone with ample opportunity to struggle with eating disturbances as food is often used as a means of communication. However, there was still a hesitancy to assign that to an ED presentation.

The experience of ED as not a label for "us" could be attributed to the idea that an ED label carries inferences about an individual's mental health state, their relationship with food, and their body perceptions. There may also be an assumption that DE is not as serious or concerning as an ED. Considering that participants described how stigmatising mental health labels can be within Black cultures, DE may feel more acceptable. Participants discussed the lens through which Black women are viewed and how this is often informed by regressive stereotypes. Black women are often perceived as strong by others in society which renders them less able to be seen as vulnerable and emotional beings. Added to this, there is an internal pressure to be "magic" or "excellent" which is also at odds with being vulnerable. It could be theorised that this may lead Black women with eating disturbances to feel anomalous, exacerbating feelings of isolation or otherness in both the wider culture and within their own culture. Therefore, making it harder for Black women to be forthcoming about their difficulties.

To an extent previous literature perpetuates this narrative by describing how Black women are somehow buffered against developing eating disturbances (Grabe & Hyde 2006; Perez & Joiner, 2002).The Sociocultural perspective suggests that a strong ethnic identity might protect individuals from body image concerns and the associated negative outcomes as there is a weak identification with mainstream thin ideals (Cotter et al., 2013). To that end, Black women are less likely to see themselves as overweight (Webb et al., 2013), and find larger frames more physically appealing (Barroso et al., 2010). Although, this can be perceived as a protective factor, findings to support this idea have been inconsistent. Furthermore, the narrative that Black women are buffered against EDs and DE may inadvertently reinforce the stereotype that eating pathologies are a predominantly "White"

phenomena resulting in the continued exclusion of an already marginalised group. Additionally, the predominant narratives of EDs focus on White women and there is a lack of representation and focus on Black women in scientific social studies. The consequence of this may be that the constructed image of a Black woman's difficulties relates to their differences to White women. Thus, Black women are required to fit into ED parameters that were developed to the exclusion of them. Katzmarzyk et al. (2012) reported that optimal BMI and waist circumference were higher in African American women than White women. Therefore, using BMI as an initial indicator of the presence of an ED may not consider that Black women may be healthy at a higher BMI. What might be considered problematic may present at a different, possibly higher threshold.

Participants in the present study discussed how the beauty ideals and standards that are present in mainstream media have moved away from a thinness ideal to incorporate a curvier body ideal. The shift in trends has meant that where previously, Black women might have felt under pressure to achieve standards of beauty in other areas of their physical appearance, such as skin colour, and hair texture (Hall, 1995). They may now face additional pressure to assimilate to the new mainstream body ideals as they more closely resemble a body shape that is associated with Black women. Participants noted that eating disturbances might be driven by the idea that the new body ideal is attainable by modifying their diet. It could be that the motivation for wanting to obtain this body ideal is for Black women to feel more *visible* within society. Interestingly, although the newer body ideal is perceived as achievable, participants described that it is still a narrowly defined conception of beauty, because more often it is only seen as beautiful on people who are not Black. Acculturative stress events such as marginalisation, perceived discrimination and racism are thought to contribute to EDs within ethnic minority populations as they directly affect how people of colour exist in their bodies (Gordon et al., 2010).

Participants described how acculturative stressors, such as lack of representation and feeling marginalised, were exacerbated by the availability and accessibility of social media. Gerbner et al. (2002) described how repeated exposure to media content can lead people to accept media portrayals as a representation of reality. This exposure is linked to a general dissatisfaction with body image in women and increased endorsement of DEBs (Grabe et al., 2008). Kelch-Oliver & Ancis (2011) noted that Black women are not protected from body image issues, which is a reliable predictor of eating pathology (Stice & Shaw, 2002; Cotter et al., 2013). Therefore, it could be reasoned that frequent exposure to media content where Black women are not represented could create a two-fold effect increasing the likelihood of DEB.

4.1 Study Limitations

Only those who identified as women were included in this study. Therefore, the findings may not represent the understanding/views of individuals who are gender non-confirming. Furthermore, all participants were self-selecting and the majority (9) were students (from A level to Doctorate level) or working professionals and seven had a psychology background. It is therefore possible that the present study might only reflect the understanding and experiences of a very select group that may not reflect the wider Black female diaspora.

Eleven of the participants were from one of three ethnic backgrounds; Jamaican, Nigerian or Ghanaian. Although this may be reflective of the representation found within Universities (the main recruitment demographic), the study may not reflect the wider Black British majority which includes other nationalities/ethnicities who may have been living in the UK for a significant period of time, but not born in the UK.

Finally, a limitation and strength of the research is that the researcher is a Black British woman. The findings were aligned with the researcher's experiences and understanding. Importantly, attempts were made to mitigate confirmation bias, through a bracketing interview. The researcher used supervision, a reflective journal and memo writing, to ensure that the theory was grounded in the data presented rather than her assumed knowledge.

4.2 Research Implications

The method of data collection in this qualitative study was through individual interviews. Alternative methods such as focus groups could add a deeper understanding of how young Black British women conceptualise ED and DE. This is particularly pertinent as many participants described the idea of a collectivist culture. Furthermore, subsequent studies should actively seek Black female participants from different socioeconomic, educational and professional backgrounds. The inclusion of Black men and Black people who identify with the LGBTQIA community in future studies may further diversify ED literature. Members of the LBGTQIA community are more likely to suffer with EDs (Parker & Harriger, 2020) and Black people who identify within this community have at least as high a prevalence of EDs as White individuals in this community (National Eating Disorder Association, 2018)

Future research may wish to explore how young Black women have experienced ED or DE, from diagnosis to treatment, as well as investigate clinicians' experiences of treating Black women with ED or DE to further understand facilitative factors and barriers in assessment, diagnosis, and treatment within this population.

4.3 Clinical Implications

The theoretical model developed within this research, identifies where different systems could make changes in how they understand EDs in young Black British women. Preventative strategies and public health initiatives that target groups such as Black women may increase mental health literacy, alongside increasing awareness and destigmatising EDs. The present study suggests that the lack of representation in wider society severely impacts Black women's ability to recognise and identify ED pathologies within themselves. Therefore, increased representation within the healthcare system, education system and within the media of Black women with EDs is important. This would develop and provide prominent narratives for Black women and further destigmatise EDs. Furthermore, schools could take advantage of The National Eating Disorder Awareness week to provide a forum for psychoeducation about EDs. This could include sharing alternative experiences of ED that challenge the dominant white narrative of EDs. This may help to increase cultural competence amongst young people, educators and the wider society.

Care and consideration should be given to the unique and conflicted relationship that Black women have with the healthcare system. To address the inherent power imbalance, it may be useful for frontline clinicians (i.e. GPs) to understand and employ the principles of Power Threat Meaning Framework (PTMF; Johnstone & Boyle, 2018) in their approach to engaging with Black women and to challenge and change their narratives of EDs. By being aware of how power, threat, and the threat response operate within the lives of Black women, clinicians may gain a better understanding of how to intervene based on what meaning is made from the difficulties described. This may be more reliable than using standard measures to evaluate symptoms that may not be clinically relevant to Black women (Kelly et al., 2012). The National Eating Disorders Association (NEDA) recommended that ED outreach efforts must be attentive to factors affecting minority populations such as patterns of acculturation, different world views, values and beliefs, effects of oppression, language barriers, and

individual differences (NEDA, 2017). Moreover, as the current study suggests the Eurocentric standpoint used to generate diagnostic terms within EDs are not helpful for Black women. The PTMF may allow clinicians to formulate a person's distress within the context of relationships, life events, and social factors which may provide an alternative to diagnostic categories and allow the clinician to use their judgement to make an appropriate referral.

Black women may not refer to their eating disturbances as an ED and may prefer to identify with DE as a label for their difficulties. A narrative approach may be helpful when working with Black women with ED or DE. Narrative therapy is underpinned by social constructivism, which assumes that life events are inherently ambiguous, and meaning is constructed largely by influences from family, culture, society and how language is used (Semmler & Williams, 2000). Emphasis is placed on the meaning given to personal experiences which influence how individuals see themselves and the world around them (Wallis et al., 2011). Whilst traditional modes of therapy might require cultural adaptations, narrative therapy provides a framework to explore implicit cultural, social, and political assumptions influencing both the clinician and the client (White & Epston, 1990). Current theories about EDs do not consider context, intersectionality, collectivist culture, and how the historic mistrust of services might influence how an ED presents in Black women. Allowing these women to collaboratively construct the narrative around their experience and how they make sense of it, may allow them to feel visible and heard within the healthcare system. Narrative Therapy retains sensitivity to multicultural processes because of the assumption that difficulties and distress are manufactured in social contexts rather than within the individual (Semmler & Wlliams, 2000).

Similarly, the use of a Black feminist therapeutic perspective may be a more practical way to centre the reality of Black women within the therapeutic process (Jones & Harris, 2019). Black feminist therapy includes interventions that assist Black women in shifting their perspectives of their life situations from models of pathology to those of wellness (Jones, 2015). This is done by empowering

Black women to recognise how internalising stereotypes and harmful notions of Black womanhood can contribute to cognitive dissonance and negative psychological symptoms (Jones & Harris, 2019). Furthermore, allowing Black women to separate their personal struggles from the structural constraints of racism, sexism, classism and homophobia (Jones & Guy-Sheftall, 2015); locating difficulties as external to themselves as part of the therapy process, may allow Black women to experience liberation from internalising negative cultural messages which may underpin their eating pathologies.

5.0 Conclusion

This research study is the first in the UK to present a theoretical model of how young Black British women conceptualise EDs and DE. Participants understood EDs to be a complex phenomenon underpinned by several factors which they have a cognitive awareness of but no personal connection to. DE was identified as a concept that may provide Black British women with an accessible framework in which to understand their own personal experiences or the experiences of others within their culture with eating distress. The model further highlights how family, education, healthcare, and societal systems influence and inform Black British women's understanding of food and eating which is impacted by the felt absence of a place for Black women within society.

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Chapter Three

A Reflective Account: Understanding Power Threat and Meaning in the Research Journey

Overall Chapter Word Count (excluding abstracts, tables, figures, references and appendices): 3,266

1.0 Introduction

This chapter presents my personal reflections on the process of conducting this research. Included within this chapter are my reflections on selecting the research topic, conducting interviews and analysis and how the process of undertaking this research has influenced my personal and professional development. In addition, I will consider how current global events have influenced my relationship to the research. This reflective chapter has been guided by a reflective journal written throughout the course of the research process and memos written at the stage of analysis within the research.

Reflective practice is a form of metacognitive competence which involves questioning our own ways of being, relating and acting (Hibbert & Cunliffe, 2015). Reflection is thought to be the key to greater self-awareness, enhancing professional expertise, clinical decision making and judgement and enhanced patient care (Sendiack, 2013; Lavender, 2003). Engaging in reflection and reflective practice has been recognised by The British Psychological Society (BPS) as an essential attribute for psychologists' professional competency and continued professional development (BPS, 2017).

Mortari (2015) proposes that reflection in research practice should not be limited to the practical aspects of the research process but extended to the mental experience which constructs the meaning about practice. This is especially true of qualitative research where there is an openness required of the researcher to accept that they are part of the research (Finlay, 1998). Although I was mindful of my own beliefs and assumptions and how this might influence my research project, it was very different to reflect on the experience of conducting research as opposed to clinical experiences.

The Power Threat Meaning Framework (PTMF; Johnston & Boyle, 2018) was introduced by the BPS as a new perspective on why people may experience forms of distress and offered an alternative to more traditional models based on psychiatric diagnosis. The PTMF integrates power, threat and threat responses to understand how individuals make sense of difficult experiences. Furthermore, it

examines how messages from wider society can heighten feelings of shame, self-blame, isolation, fear and guilt (Johnstone & Boyle, 2018). My research study included Black British women as the target demographic, and I believed that there would be issues of power inherent to the conversation because of how Black women are viewed in society. So much are the unique problems of oppression faced by Black women that two separate terms; "Intersectionality[50]" (Crenshaw, 1989) and "Misogynoir[51]" (Bailey, 2018) were coined. I thought it would be interesting to structure my personal reflections using the concepts of the PTMF (outlined in Table 7) as anchor points throughout this narrative. Additionally, feeling less confident in my research and academic abilities, using the concepts of the PTMF feels applicable to think about my experiences of conducting research at doctorate level.

Table 7

Power Threat Meaning Framework Concepts

Concepts	Prompts
Power	How is **Power** operating in your life? What has happened to you?
Threat	What kind of **Threats** does this pose? How did this affect you?
Meaning	What is the **Meaning** of these situations and experiences to you?
Threat Responses	What kind of **Threat Response** are you using? What did you have to do to survive?
Power Resources	What access to **Power Resources** do you have? What are your strengths?
Framework	What is your story? How does this all fit together?

[50] Intersectionality- a description of how race, class, gender and other individual characteristics intersect with one another and overlap (Crenshaw, 1989).
[51] Misogynior- Misogyny directed towards Black women, where race and gender play a role in bias (Bailey, 2018).

1.1 Topic Selection

Picking a thesis research topic was initially very daunting; like many things in my life, my initial idea was inspired by my daughter and something she said to me when she was younger. She had just started school and one day she asked me why her skin was not as pretty as her peers. In that moment I had many different thoughts and emotions. I wondered what had happened to make her feel like that and I felt powerless and sad. As much as I wanted to instil in her a sense of pride in her identity, I wondered whether she would always feel othered. Originally, I wanted to explore how being Black influences self-identity in young girls. Exploring the idea that the complexity of identity formation may be compounded by issues such as racial identification, racial preference and group orientation (Spencer & Markstrom-Adams, 1990) fascinated me. Although, this was considered a topic potentially too big to undertake within the time frame, it confirmed to me that I wanted to do something with Black women. Part of my reasoning was that I would love to contribute to something that could possibly have positive implications for my daughter and her confidence in herself as a Black woman in the future.

Whilst I knew that I wanted to do something that looked at Black women and their experiences or issues that concern this specific demographic, I also had reservations about doing so. I knew that looking at a demographic that I was a part of, would mean that I would have certain assumptions and biases and a vested interest in the outcomes. I considered the impression people would have of me if I were to do a study focusing on Black women, wondering whether people would think that I was using my thesis as a soapbox or as an easy option. I think that Black women often find themselves having to second guess the decisions they make, especially when it comes to speaking up for other Black women or highlighting issues of concern. I was very aware of my position as a Black woman trying to enter what the BPS recognises is a White-dominated profession (Turnpin & Coleman, 2010). Collins (1986) coined the term “outsider-within” and described how outsiders-within can gain access to the knowledge of the group (within) but the power structure within the group remains unequal (outsider).

Clinical Psychology has attempted to tackle diversity issues for decades and acknowledges that there is a longstanding lack of diversity within the profession (Turpin & Coleman, 2010). Whilst there are steps being taken to address this, it is acknowledged as a systemic and structural issue (Bains, 2019). As someone who identifies with the label outsider-within, there is a unique position held in being able to appreciate and relate to Black women and their narratives while understanding the implications for those conducting research from within. I felt that within the space I occupy being on the Clinical Doctorate I had an opportunity to be directly involved in aiding systemic change by giving voice to an often-marginalised group. The increasing complexity of Britain's sociocultural ethnoscape is reflected in the surge of racial and ethnic studies across different disciplines (Meer & Nayak, 2013). To be able to contribute to a growing literature base means being able to give a little bit of power to Black women to share their stories, viewpoints and experiences.

Additionally, I felt more passionate about identifying a topic that would contribute to understanding the issues and complexities surrounding the experiences of Black women. Intersectionality is an analytical framework describing how multiple aspects of a person's social and political identities intersect at a micro level of individual experience to create different modes of discrimination and privilege (Bowleg, 2012). Understanding that the words *female* and *Black* are not mutually exclusive was part of the process of identifying a research topic. When myself and my research team identified the final topic, it felt compatible with the original vision I had for my research.

1.2 Interviews and Analysis

In the planning stages of the project, I had intended to recruit participants and arrange face to face interviews. Unfortunately, due to the COVID-19 pandemic, this was not a viable option. Instead, interviews were conducted via an online video platform or telephone. As a clinical practitioner I rely on non-verbal communication just as much as verbal communication and so my preferred method of relating to people, is in person.

For myself, observing people provides the foundation on which the verbal content rests. “Verbal communication is discrete and begins and ends with words or sounds produced” (Grzybowski et al., 1992). As someone who places value in their interpersonal skills, I initially felt I would be at a disadvantage not conducting the interviews in a format that I was familiar with. This left me feeling like I had lost my power resource. Furthermore, I was worried about how well an online platform would help with attunement or containment for participants, which felt threatening. There was a feeling that somehow the interviews would be conducted badly, because an online platform might be a barrier to meaningful engagement. However, I was able to reflect on remote placements and the skills used to engage with clients I was unable to see face to face and apply this to interviewing participants online. Being able to draw on these skills became a power resource and further highlighted how transferrable clinical skills can be.

I did reflect after my first interview that there was a pull towards stepping into a therapeutic role and wanting to paraphrase or interpret the participant’s answers. I was able to establish rapport quite easily with my participants and I believe this was made easier by my own social and cultural background. Fortunately, I had taken part in a bracketing interview prior to conducting my participant interviews and I had an awareness of my biases in relation to my research topic. What I had not accounted for or maybe failed to fully realise, is that over-rapport and over-familiarisation were probably equally as likely to effect objectivity (Oxford Reference Database, n.d). I had to make a point of asking for clarifications on phrases or terminology that I already understood in order to make certain concepts explicit. This was very interesting to observe as often Black people joke about a shorthand communication that you just *understand* implicitly. In hearing my participants share their viewpoints, I often found myself nodding along in agreement as I shared some of these experiences and opinions. Whilst this demonstrated active listening (Nelson-Jones, 2012), I was also aware of the need to maintain a state of active self-review whilst conducting my interviews which I am not sure I would have had to do to the same extent if I was interviewing non-Black participants. Having to be a blank slate to allow my participants to be their entire selves without interpretation or interference,

when it felt like my participants were parts of me reflecting my experiences back to me, was very challenging. On reflection, I do wonder whether this constant checking in with myself and my language did influence the rapport I had with participants. Again, this mirrored the feeling of being both an insider and outsider, which can be characteristic of qualitative approaches (Råheim et al., 2016). I was very glad of the supervision I received, which gave me an opportunity to reflect on these issues and the impact that the research topic might have on me personally. The use of memo writing aided introspection and reflection, as I noted down observations as well as my own interpretations. Being consistent in writing memos helped to keep the focus on the participants.

I noticed when giving feedback to my research supervisors about what participants had discussed, there was a tendency for me to use the term “we” to describe their experiences or opinions. I recognised that I felt a part of this group as a Black woman but knew that I had to keep myself separate so that I did not compromise the integrity of the research. Moreover, there was an acute awareness of my power as a researcher, deciding what was important and significant data. I was struck by how deeply participants felt about the research topic and how passionate they were about providing insight. To that end, having to pull quotes from interviews to include in my Results section was one of the hardest tasks I had to undertake. Deciding what quote might be the most impactful or poignant, at times felt like an abuse of power. The majority of participants spoke about an inherent mistrust of healthcare services and as someone who works within this system it was as if the power imbalance was being re-enacted. A recurring theme within the data was the idea of visibility and it felt like I was rendering some participants invisible, even though they all contributed to the research. In a way, it was almost antithetical to the reason why I wanted to conduct this research. Being so close to the research personally, created a duality; the research project was both a source of power, in a sense that it motivated me to want to do my best. In the same vein it was source of threat, as the fear of failing was twofold, I would be failing academically and failing a group I identified with.

1.3 Global Events

I do not think I could use the PTMF to reflect on the research process without highlighting important events that made very real to me, my own position of power and perception of threat. The killing of George Floyd ignited a call for racial justice around the world. I sat through the video recording of the incident in its entirety. I remember thinking I should stop watching because I will never be able to unsee it, but the thought of turning away felt like a betrayal. I was heartbroken, outraged, anguished, but most disturbingly, I was not surprised. This was not new, and this was not an isolated incident. The COVID-19 pandemic had forced the world to not look away and to take notice. Although this incident sparked embers of change, it bought to the forefront the very real racial trauma of Black deaths both present-day and historical.

At first, I did not understand why this affected me so much, but then I remembered "The Body Keeps The Score" by Van Der Kolk (2015). Racial trauma is a visceral pain and the intergenerational nature of this trauma impacts individuals and social groups in a myriad of ways (Tynes et al., 2019). For myself, I felt an exhaustion and a disconnect from things that I had previously found comfort in. Anti-Blackness is a term coined to describe society's inability to recognise Black humanity (Bledsoe & Wright, 2018) and it felt as if Black people collectively, had to justify their anger, outrage and despair. For a few weeks after the incident, the world I had previously felt fine in, felt much more threatening and I felt powerless. I had not experienced this before, and it forced me to reflect how fragile the illusion of safety is for certain people.

I noticed in the interviews that there was an openness and an unwavering honesty when discussing systemic issues and risk factors that may contribute to Black women developing EDs. It may have been my own interpretation or feeling, but I think that the interviews were also a forum to make sense of and unpack the impact of current events, especially at a time when interactions and conversations were limited amongst family and friends.

A particular quote from one of my participants stood out and captured the tone of some of my interviews; *" I think self-love in Black women and Black British people is an affront to the structure of society." [P007; 602]*. I wondered whether thoughts and feelings such as this were a coming from a place of threat or power considering events that had transpired. Knowing how I had felt I could only imagine how some of my participants had internalized events and how they had woven it into their narratives to make sense of. Whilst my bracketing interview highlighted my personal experiences and viewpoints, this was unexpected and an area of bias I had not considered. Consequently, I had to pay close attention to how I coded and analysed to make sure that I was not giving undue weight to phrases and quotes that I found powerful based solely on my own interpretation.

1.4 Personal and Professional Development

At the beginning of the research process I had not given much consideration to how I might be affected. My research supervisors checked-in at regular intervals to make sure that I was coping and managing alongside my other personal commitments. For the most part I thoroughly enjoyed the initial steps of the research process. What I realised is that there was an emotional cost to undertaking this research. It was hard to hear people who looked like me and could have been me, talk about the different ways they feel let down, marginalised, overlooked and othered. At the core of my wanting to be a Clinical Psychologist is the need to alleviate distress in others and it was hard to just be a researcher in this instance. This research has made me more acutely aware of how power and threat are interwoven in various systems. It also highlighted instances where I might be in a position of power in my life, namely as a clinician.

Personally, this process has afforded me the opportunity to really think about my place in society, what roles I occupy and how they are inextricably linked with my identity as a Black woman. Much of my experiences and how I move through life will be viewed through this lens and that is not a negative thing. This is very much an unexpected outcome of this research. I did not realise how much it would hold up a mirror to my own viewpoints and experiences. Consequently, I was not prepared for how

invested I became in the research and in trying to make sure that it is perfect. I initially embarked on a journey of research as part of a process of qualifying from the Clinical Doctorate Course. However, I think that each stage of the research process has inspired personal and professional growth.

In speaking to people outside of the research process about my thesis I started to have more in-depth conversations about food, eating, weight and shape concerns with family and friends. I have always known that discourse is essential in destigmatising mental health but have felt hesitant in applying that in my personal life in conversations with friends and family. I now realise more than ever that it is these kinds of conversations that are likely to make the most difference. I was often reminded of the phrase “knowledge is power” during my research. In having these conversations there is a sharing of knowledge and insight that creates power. Being part of that process and hearing friends talk about food and eating in ways that they have not considered before has been inspiring.

Throughout my journey on the Clinical Doctorate, I have come to realise many things about the type of clinician I am, although this still evolving. I have at times found it hard to be boundaried with clients when I feel a personal connection and usually, I reconcile this by reminding myself that boundaries are protective for both clinician and client. During the research process I put more of an emphasis on boundaries because of how important I believe this research to be. Boundaries create healthy parameters in which to work towards an end goal that is bigger than the clinician. Undertaking this research has highlighted that I can create boundaries without sacrificing authenticity and sincerity which I value immensely.

Coming into the Clinical Doctorate I always knew that research and written academic work is where I had the least confidence and would have considered myself more of a therapist than an academic. However, this process has highlighted where the two overlap and where therapeutic skills were useful in conducting research. Similarly, skills that I used in conducting research will help immeasurably in clinical work. Using the PTMF has been invaluable in considering threat and power within the research

and the meaning that I made of this. Moreover, I hope to remember the importance of power, threat and meaning as I progress in my career as a Clinical Psychologist.

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Appendices

Appendix A. Author Guidelines for the Journal of Diabetes and Its Complications

Aims and Scope

The primary purpose of *Journal of Diabetes and Its Complications* is to act as a source of information, usable by those caring for patients with diabetes mellitus who are thereby at risk for development of those complications which all too often appear with time. While our primary aim is to assist the practitioner in his/her care of such patients, and to afford access to information that may allow the prevention of such complications, it is the Editors' wish to function as a forum for that information which, while still experimental, may shed light upon current thinking of those active in the fields appropriate to the aims of *Journal of Diabetes and its Complications*.

In addition to general articles on clinical aspects of diabetes mellitus, *Journal of Diabetes and its Complications* also presents articles on basic research in all areas of diabetes and its related syndromes. Topics covered relevant to the diabetic patient will include diagnosis, pathogenesis, and clinical management of the following: diabetic retinopathy, neuropathy and nephropathy; peripheral vascular disease and coronary heart disease; gastrointestinal disorders, renal failure and impotence; and hypertension and hyperlipidemia. *Journal of Diabetes and its Complications* will also publish papers on the general pathogenesis and prevention of diabetes.

Criteria for initial considerations for papers submitted will be originality, statistical probability of all data, and applicability to the aims of the Journal as a whole. Additional weight will be afforded to those submissions that are concise and comprehensible. All potentially acceptable manuscripts will be subjected to the process of peer review. To aid with the peer-review process, at least five suggested reviewers whose expertise falls within the scope of the submitted manuscript must be provided. For each suggested reviewer include full names, addresses (physical and email), phone and fax numbers.

Journal Principles

All manuscripts submitted to *Journal of Diabetes and Its Complications* should report original research not previously published or being considered for publication elsewhere, make explicit any conflict of interest, identify sources of funding and generally be of a high ethical standard.

Submission of a manuscript to this journal gives the publisher the right to publish that paper if it is accepted. Manuscripts may be edited to improve clarity and expression. Submission of a paper to *Journal of Diabetes and its Complications* is understood to imply that it has not previously been published and that it is not being considered for publication elsewhere.

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:
• E-mail address
• Full postal address

All necessary files have been uploaded:
Manuscript:
• Include keywords

• All figures (include relevant captions)
• All tables (including titles, description, footnotes)
• Ensure all figure and table citations in the text match the files provided
• Indicate clearly if color should be used for any figures in print
Graphical Abstracts / Highlights files (where applicable)
Supplemental files (where applicable)

Further considerations
• Manuscript has been 'spell checked' and 'grammar checked'
• All references mentioned in the Reference List are cited in the text, and vice versa
• Permission has been obtained for use of copyrighted material from other sources (including the Internet)
• A competing interests statement is provided, even if the authors have no competing interests to declare
• Journal policies detailed in this guide have been reviewed
• Referee suggestions and contact details provided, based on journal requirements

For further information, visit our Support Center.

Before You Begin

Ethics in publishing

Please see our information pages on Ethics in publishing and Ethical guidelines for journal publication.

Ethics

Work on human beings that is submitted to the journal should comply with the principles laid down in the Declaration of Helsinki "Recommendations guiding physicians in biomedical research involving human subjects", adopted by the 18th World Medical Assembly, Helsinki, Finland, June 1964 (and its successive amendments). The manuscript should contain a statement that the work has been approved by the appropriate ethical committees related to the institution(s) in which it was performed. Studies involving experiments with animals must state that their care was in accordance with institution guidelines.

Informed consent and patient details

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Appendix B. Coventry University Ethics Certificate – Systematic Literature Review

Certificate of Ethical Approval

Applicant:	Kafui Kodjokuma
Project Title:	A Systematic Review of the risk factors involved in the development of Eating Disorders in Young People with Type 1 Diabetes.

This is to certify that the above named applicant has completed the Coventry University Ethical
Approval process and their project has been confirmed and approved as Low Risk

Date of approval:	29 Mar 2021
Project Reference Number:	P121270

Appendix C. Caldwell Assessment Framework- Blank Copy (Caldwell et al. 2011).

Question	Yes (2 points)	Partial (1 point)	No (0 points)
Q1. Does the title reflect the content? The title should be informative and indicate the focus of the study. It should allow the reader to easily interpret the context of the study. An inaccurate or misleading title can confuse the reader			
Q2. Are the authors Credible? Researchers should hold appropriate academic qualifications and be linked to a professional field relevant to the research			
Q3. Does the abstract summarize the key components? The abstract should provide a short summary of the study. It should include the aim of the study, outline of the methodology and the main findings. The purpose of the abstract is to allow the reader to decide if the study is of interest to them			
Q4. Is the rationale for undertaking the research clearly outlined? The author should present a clear rationale for the research, setting it in context of any current issues and knowledge of the topic to date			
Q5. Is the literature review comprehensive and up to date? The literature review should reflect the current state of knowledge relevant to the study and identify any gaps or conflicts. It should include key or classic studies on the topic as well as up to date literature. There should be a balance of primary and secondary sources			
Q6. Is the aim of the research clearly stated? The aim of the study should be clearly stated and should convey what the researcher is setting out to achieve			
Q7. Are all ethical issues identified and addressed? Ethical issues pertinent to the study should be discussed. The researcher should identify how the rights of informants have been protected and informed consent obtained. If the research is conducted within the NHS there should be an indication of local research ethics committee approval			
Q8. Is the methodology identified and justified? The researcher should make clear what research strategy they are adopting, i.e. qualitative or quantitative. A clear rationale for the choice should also be provided, so that the reader can judge whether the chosen strategy is appropriate for the study.			
Q9. **Quantitative Studies**: Is the study design clearly identified and a rationale provided? The design of the study e.g. survey, experiment should be identified and justified. As with the choice of strategy, the reader needs to determine whether the design is appropriate for the research undertaken			
Q10. **Quantitative Studies**: Is there an experimental hypothesis clearly stated and are the key variable identified? In experimental research the researcher should provide a hypothesis. This should clearly identify the independent and dependent variable and state their relationship and the intent of the study. In survey research the researcher may choose to provide a hypothesis, but it is not essential, and alternatively a research question or aim may be provided			
Q11. **Quantitative Studies:** Is the population identified? The population is the total number of units from which the researcher can gather data. It may be individuals, organisations or documentation. Whatever the unit, it must be clearly identified			

Q12. **Quantitative Studies**: Is the sample adequately described and reflective of the population? Both the method of sampling and the size of the sample should be stated so that the reader can judge whether the same is representative of the population and sufficiently large to eliminate bias			
Q13. **Quantitative Studies:** Is the method of data collection valid and reliable? The process of data collection should be described. The tools or instruments must be appropriate to the aims of the study and the researcher should identify how reliability and validity were assured			
Q14. **Quantitative Studies:** Is the method of data analysis valid and reliable? The method of data analysis must be described and justified. Any statistical test used should be appropriate for the data involved.			
Q15. **Qualitative Studies:** Are the philosophical background and study design identified and the rationale for choice evident? The design of the study e.g. phenomenology, ethnography, should be identified and the philosophical background and rationale discussed. The reader needs to consider if it is appropriate to meet the aims of the study.			
Q16. **Qualitative Studies:** Are the major concepts identified? The researchers should make clear what the major concepts are but they might not define them. The purpose of the study is to explore the concepts from the perspective of the participants.			
Q17. **Qualitative Studies:** Is the context of the study outlined? The researcher should provide a description of the context of the study, how the study sites were determined and how the participants were selected.			
Q18. **Qualitative Studies:** Is the selection of participants described and the sampling method identified? Informants are selected for their relevant knowledge or experience. Representativeness is not a criteria and purpose sampling is often used. Sample size may be determined through saturation. Is the method of data collection auditable? Data collection methods should be described and be appropriate to the aims of the study.			
Q19. **Qualitative Studies:** Is the method of data analysis credible and confirmable? The data analysis strategy should be identified, what processes were used to identify patterns and themes. The researcher should identify how credibility and confirmability have been addressed.			
Q20. Are the results presented in a way that is appropriate and clear? Presentation of data should be clear, easily interpreted and consistent			
Q21. Is the discussion Comprehensive? In quantitative studies the results and discussion are presented separately. In qualitative studies these may be integrated. Whatever the mode of presentation the researcher should compare and contrast the findings with that of previous research on the topic. The discussion should be balanced and avoid subjectivity			
Q22. **Quantitative Studies:** Are the results generalizable?			
Q23. **Qualitative Studies:** Are the results transferable?			
Q24. Is the conclusion comprehensive? Conclusions must be supported by the findings. The researcher should identify any limitations to the study. There may also be recommendations for further research or if appropriate implications for practice in the relevant field.			

Appendix D. Reviewer Quality Assessment Scores

Papers	Title	Authors	Abstract	Rationale	Literature Review	Aim	Ethical Issues	Methodology identified/justified	Quan/ Qual: Study Design	Quan: Hypothesis/aim Qual: Concepts identified	Quan: Population Identified	Quan: Population Sample, Qual: Participant selection/Auditable	Quan: Data collection valid/reliable, Qual: Data collection auditable	Quan/Qual: Method of data analysis credible	Results	Discussion	Quan: Generalisability Qual: Transferable	Conclusion	Total Score
Araia et al., 2020	2	2	2	2	2	2	1	1	1	2	2	2	2	2	2	2	1	2	**32**
Cherubini et al., 2018	2	2	2	2	2	2	1	1	1	2	2	2	2	2	2	2	2	2	**33**
Eisenberg et al., 2016	2	2	2	2	2	2	1	2	1	2	2	2	2	2	1	2	1	2	**32**
Grylli et al., 2005	2	2	2	2	2	2	1	1	1	2	2	1	2	2	2	2	1	2	**31**
Howe et al., 2008	2	2	2	2	2	2	1	0	1	2	2	2	2	2	2	2	1	2	**31**
Kaminsky & Dewey, 2013	2	2	2	2	2	2	1	2	1	2	2	2	2	2	2	2	1	2	**33**
Meltzer et al., 2001	2	2	2	2	2	2	0	1	1	2	2	2	2	2	2	2	1	1	**30**
Peterson et al., 2018	2	2	2	2	2	2	0	1	2	2	2	2	2	2	2	2	1	2	**32**
Schwartz et al., 2002	2	2	2	2	2	2	1	1	1	2	2	2	1	2	2	1	1	2	**30**
Sellami et al., 2020	2	2	2	1	2	2	2	1	1	2	2	2	2	2	2	1	1	1	**30**
Sein et al., 2020	2	2	1	1	1	2	1	2	1	1	-	1	2	2	1	2	1	2	**25**
Svensson et al., 2003	2	2	1	1	1	0	1	1	1	1	2	2	2	2	2	1	1	1	**24**
Troncone et al., 2020	2	2	2	2	2	2	1	1	1	2	2	2	2	2	2	2	1	2	**32**

Tse et al., 2012	2	2	2	2	2	1	1	1	1	1	2	1	2	2	2	2	1	2	**31**
Wilson et al., 2015	2	2	2	1	2	1	1	1	2	2	2	2	2	1	2	2	1	2	**30**
Wisting et al., 2015	2	2	2	2	2	2	1	0	0	2	2	2	2	2	2	2	1	2	**30**

Appendix E. Independent Rater Quality Assessment Scores

Papers	Title	Authors	Abstract	Rationale	Literature Review	Aim	Ethical Issues	Methodology identified/justified	Quan/ Qual: Study Design	Quan: Hypothesis/aim Qual: Concepts identified	Quan: Population Identified	Quan: Population Sample, Qual: Participant selection/Auditable	Quan: Data collection valid/reliable, Qual: Data collection auditable	Quan/Qual: Method of data analysis credible	Results	Discussion	Quan: Generalisability Qual: Transferable	Conclusion	Total Score
Araia et al., 2020	2	2	2	2	2	2	1	1	1	2	2	2	2	2	2	2	1	2	**32**
Cherubini et al., 2018	2	2	2	2	2	2	1	1	1	2	2	1	2	2	2	2	2	2	**32**
Eisenberg et al., 2016	2	2	2	2	2	2	1	2	1	2	2	2	2	2	1	2	1	2	**32**
Grylli et al., 2005	2	2	2	2	2	2	1	1	1	2	1	1	2	2	2	2	1	2	**30**
Howe et al., 2008	2	2	2	2	2	2	1	0	1	2	2	1	2	2	2	2	1	2	**30**
Kaminsky & Dewey, 2013	2	2	2	2	2	2	1	2	1	2	2	2	2	2	2	2	1	2	**33**
Meltzer et al., 2001	2	2	2	2	2	2	0	1	1	2	2	1	1	2	2	2	1	1	**28**
Peterson et al., 2018	2	2	2	2	2	2	0	1	2	2	2	2	2	2	2	2	1	2	**32**
Schwartz et al., 2002	2	2	2	2	2	2	1	1	1	2	2	1	1	2	2	1	1	2	**29**
Sellami et al., 2020	2	2	2	1	2	2	2	1	1	2	2	2	2	2	2	1	1	1	**30**
Sein et al., 2020	2	2	1	1	1	2	1	2	1	1	-	1	2	2	1	2	1	2	**25**
Svensson et al., 2003	2	2	1	1	1	0	1	1	1	1	2	2	2	2	2	1	1	1	**24**

Troncone et al., 2020	2	2	2	2	2	2	1	1	1	2	2	2	2	2	2	2	1	2	**32**
Tse et al., 2012	2	2	2	2	2	1	1	1	1	1	2	1	2	2	2	2	1	2	**31**
Wilson et al., 2015	2	2	2	1	2	1	1	1	1	2	2	2	2	1	2	2	1	2	**29**
Wisting et al., 2015	2	2	2	2	2	2	1	0	0	2	2	2	2	2	2	2	1	2	**30**

Appendix F. Inter-Rater Reliability Coefficient (Kappa) Scores

Paper	Kappa Score
Araia et al., 2020	κ = 1.000
Cherubini et al., 2018	κ = .824
Eisenberg et al., 2016	κ = 1.000
Gyrilli et al., 2005	κ = .870
Howe et al., 2008	κ = .860
Kaminsky & Dewey 2013	κ = 1.000
Meltzer et al., 2001	κ = .769
Peterson et al., 2018	κ = 1.000
Schwartz et al., 2002	κ = .880
Sellami et al., 2020	κ = .870
Sien et al., 2020	κ = 1.000
Svensson et al., 2003	κ = 1.000
Troncone et al., 2020	κ = 1.000
Tse et al., 2012	κ = 1.000
Wilson et al., 2015	κ = .870
Wisting et al., 2015	κ = 1.000

Appendix G. Overview of Studies included in Systematic Literature Review

Of the 16 studies included, seven studies were from North America (Eisenberg et al., 2016; Howe et al., 2008; Kaminsky & Dewey, 2013; Meltzer et al., 2001; Peterson et al., 2018; Schwartz et al., 2002; Tse et al., 2012), six were from Europe (Cherubini et al., 2018; Grylli eta l., 2005; Troncone et al., 2020; Svensson et al., 2003; Wilson et al., 2015; Wisting et al., 2015), and one each from Australia, Africa and Asia (Araia et al., 2020; Sellami et al., 2020; Sien et al., 2020).

The studies employed a range of measures to assess eating disturbances amongst young people with type one diabetes. Six of the studies used the DEPS(R) as a measure (Aria et al., 2020; Cherubini et al., 2018; Eisenberg et al., 2016; Howe et al, 2008; Troncone et al., 2020; Tse et al., 2012). Five studies used a version of the EDI (Grylli et al., 2005; Kaminsky & Dewey, 2013; Meltzer et al., 2001; Peterson et al., 2018; Svensson et al., 2003), two used a version of the Eating Attitudes Test (Grylli et al., 2005; Sellami et al., 2020). One used the EDE-Q (Schwartz et al., 2002) and three studies also employed the Eating Disorders Examination Interview (Grylli et al., 2005; Wilson et al., 2015; Wisting et al., 2015).

Sample sizes within the studies ranged from *N*= 477 (Araia et al., 2020) to *N*= 15 (Sien et al, 2020) and the mean age of participants ranged from 12.9 (Peterson et al., 2018) to 17.1 (Sellami et al, 2020). There were two single-sex studies included (female; Schwartz et al., 2002 & male; Svensson et al., 2003) and the remaining studies recruited between 27-54% male participants and 46-73% female participants. Three studies employed control samples (Kaminsky & Dewey et al., 2013; Svensson et al., 2003; Troncone et al., 2020).

Appendix H. Study contribution to Main Themes

Study	Themes											
	Biological Risk Factors		Physiological Risk Factors			Psychosocial Risk Factors						
						Psychological Risk Factors				Social Risk Factors		
	Sex	Age	BMI	Metabolic/ Glycaemic Control	Satiety	Body Image Concerns	Psychological Distress	Temperament & Personality	Attitudes	Pressure	Treatment Adherence	Quality of Life
Araia et al., (2020)	■	■	■	■		■	■	■	■			■
Cherubini et al., (2018)	■		■	■							■	■
Eisenberg et al., (2016)								■				
Gyrilli et al., (2005)	■		■					■				
Howe et al., (2008)	■	■		■	■	■					■	
Kaminsky & Dewey (2013)						■		■				
Meltzer et al., (2001)	■	■	■			■						
Peterson et al., (2018)	■		■		■	■	■					

Schwartz et al., (2001)												
Sellami et al., (2020)												
Sein et al., (2020)												
Svensson et al., (2003)												
Troncone et al., (2020)												
Tse et al., (2012)												
Wilson et al., (2015)												
Wisting et al., (2015)												

Appendix I. Author Guidelines for The Journal of Cross-Cultural Psychology

Manuscript Submission Guidelines:

Journal of Cross-Cultural Psychology (*JCCP*) publishes material in three categories: (1) regular, unsolicited manuscripts, (2) brief reports, and (3) special issues. Summary details of each category are as follows:

1.Regular, Unsolicited Manuscripts. This is *JCCP*'s main emphasis. See Aims and Scope for a detailed description of appropriate manuscripts.

Manuscripts should be submitted electronically to http://mc.manuscriptcentral.com/jccp. Authors will be required to set up an online account on the SageTrack system powered by ScholarOne. Manuscripts will be sent out anonymously for editorial evaluation. Obtaining permission for any quoted or reprinted material that requires permission is the responsibility of the author. Submission of a manuscript implies commitment to publish in the journal. Authors submitting manuscripts to the journal should not simultaneously submit them to another journal, nor should manuscripts have been published elsewhere in substantially similar form or with substantially similar content. Authors in doubt about what constitutes prior publication should consult the Editor.

Manuscript length should normally be 15 to 35 double-spaced, typewritten pages. Longer papers will be considered and published if they meet the above criteria. Manuscripts should be prepared according to the most recent edition of the American Psychological Association Publication Manual. Manuscripts are reviewed by the Editorial Advisory Board. Allow up to 3 months for a publication decision and up to 1 year for publication.

2. Brief Reports. Accepted Brief Reports should be no more than 10 double-spaced manuscript pages long, including title page, references and any tables.

3. Special Issues. An important part of *JCCP*'s publication policy is the periodic publication of special issues or special sections of regular issues. Current needs, emerging trends, and readership interest guide the publication of material in this

category. Ideas or suggestions for special issues or special sections should be discussed with Walter J. Lonner (Walter.Lonner@wwu.edu), Founding and Special Issues Editor, or other members of the Editorial Advisory Board, especially current Editor, Deborah L. Best (best@wfu.edu).

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As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

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Appendix J. Interview Guide

ED- Eating Disorders

DE- Disordered Eating

YBBW- Young Black British Women

Interview Guide

- Could you tell me a little bit about yourself?

(Age, area of study, how things are, family, friends, interests etc)

- What is your understanding of the terms "eating disorders" and "disordered eating"

(Do the two terms mean the same thing? Are they different? What do you think informs your understanding of these terms?)

- Could you describe someone who might be struggling with ED/DE?

(What might they look like? What characteristics would they have? How might you know they had ED/DE- Maybe ask participants to come up with 5 characteristics of someone with ED/DE)

- What (if any) effect do you think your ethnicity and cultural background has on your understanding of ED/DE?

(Refer back to the characteristics- did ethnicity factor into your depiction of someone struggling with ED/DE? Why? Why not? Do you think it is relevant?

- What do you think ED/DE might look like for a YBBW?

(What characteristics might they have? What might their relationship with food look like? Is it different to the type of person you described earlier? If different- why?)

- What might leave YBBW at risk of ED/DE?

(Why do you think this might be? Might these be different risk factors from other ethnicities?)

- What might protect YBBW from developing ED/DE?

(Why might this be? Might these be different protective factors from other ethnicities?)

- What is your understanding of the term "Western Ideals of Beauty"?
- How do these "western ideals of beauty" relate to, if at all, the development or maintenance of ED/DE in YBBW?

(How does this, if at all, fit into your ideals of beauty? Might this be different for different generations (mother, grandmother)? Might it be different for people not born in the UK? Why/Why not?)

- What might be important to think about when supporting or treating YBBW with ED/DE?

  (What might be helpful for the family to do/not do? What might be helpful for healthcare clinicians to do/not do? Environment of treatment?)

- Do you have any other thoughts/insights into what we have been discussing?

Appendix K. Coventry University Ethics Certificate- Empirical Research Study

Certificate of Ethical Approval

Applicant:

Kafui Kodjokuma

Project Title:

How do young Black British Women conceptualise Eating Disorders and Disordered Eating?

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

27 June 2020

Project Reference Number:

P103184

Appendix L. Additional Ethics Considerations

There were several ethical considerations due to the nature of the subject and population of interest.

According to the BPS Code of Human Research Ethics (2014) participants should be informed of all aspects of the research or intervention which influence their willingness to participate. Informed consent was obtained from all participants before conducting the interviews. Potential participants were sent the Participant Information Sheet which gave clear and explicit information about the research project, what would be involved and data management in accordance with government legislation. Potential participants were also sent a Consent Form to sign and return confirming their understanding of the information provided and agreement to take part in the research project. Verbal consent was obtained at the time of interview.

EDs and DE are sensitive subjects that have the potential to cause distress and the proposed sample population are already underrepresented in treatment literature (Bell & Knolls, 2013). As such a protocol was developed to manage any potential disclosures of harmful behaviours considered to be a risk and this was described within the Participant Information Sheet at the time of providing informed consent.

Although the proposed research question did not require participants to have a clinical diagnosis there is the ethical consideration of intervention. Therefore, as part of the consideration of risk, participants were given information about how to access emotional support and signposting to helpful resources as part of the debrief protocol (Debrief Sheet; Appendix Q) which was sent out to participants upon completion of the interview.

Appendix M. Social Media Recruitment Poster

Appendix N. Informational Recruitment Poster

How do young Black British women conceptualise (think about and understand) eating disorders and disordered eating?

Who Am I? My name is Jacqui Kodjokuma and I am a **Clinical Psychology Doctoral Trainee** currently working on my thesis at the University of Coventry and Warwick University.

Who Am I looking For? Young black women (18-25) from Black-African or Black-Caribbean decent who were born in the UK.

What Will You Be Asked To Do?

You will be asked to take part in an interview that will last no longer than 70 minutes. Considering the government restrictions and recommendations due to COVID-19, the interviews can take place in various formats. All interviews will require your consent to be voice recorded.

- The interviews can take place over the phone.
- The interviews can be conducted via an online video platform.
- Providing that you are comfortable with this, the interviews can be conducted face to face, if government guidance at that time deems this safe to do so.

In this interview I will ask you some questions about eating disorders and disordered eating, what role (if any) your ethnic and cultural background plays in your understanding of these terms and questions around beauty ideals. Please be assured that should you consider taking part in this research that all your information will be anonymised and treated with the utmost confidentiality. All information will be kept securely, and you have the right to withdraw should you no longer wish to participate.

Why Do It? An estimated 1.6 million people are directly affected by eating disorders in the UK (Beat, 2017). Currently there is limited literature available about how eating disorders might be understood within ethnic communities. There is even less literature available on black women in the UK. This research aims to increase understanding of mental health issues that may impact this under-presented community/demographic.

If you are interested: Please get in contact via email: kodjokuk@uni.coventry.ac.uk for more information or to express your interest in taking part .

This study has been approved by Coventry University Research Ethics Committee.

Thank you for taking the time out to read this request!

Appendix O. Participant Information Sheet

PARTICIPANT INFORMATION SHEET

You are being invited to take part in research on **how young Black British women conceptualise eating disorders and disordered eating**. **Jacqui Kodjokuma, Trainee Clinical Psychologist** at Coventry University is leading this research. Before you decide to take part, it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully. After reading this information sheet, you will have the opportunity to ask any questions or have any information explained further.

What is the purpose of the study?

The purpose of the research project is to try and understand how young Black British women form ideas (conceptualise) about eating disorders (ED) and disordered eating (DE). In the UK, it is estimated that 1.6 million people are directly affected by eating disorders (Beat, 2017). There is very limited information on how common eating disorders are in minority populations in the UK and even less is known about how minority populations understand, recognise, experience and recover from ED/DE. This research aims to address this gap in the current research. The findings from this research could have real world applications in terms of prevention strategies, early detection and intervention in eating disorders and culturally responsive treatment for young black women.

This research project is being undertaken as part of the fulfilment of requirements for the researcher's Doctorate in Clinical Psychology qualification.

Why have I been chosen to take part?

This research would like to talk to young Black British women (18-25) who were born in the UK. You would have responded to a recruitment leaflet for this research project and spoken to the lead researcher who would have decided that you might fit this description.

Do I have to take part?

No – it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate. Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you seek to withdraw from the study at a later date. **You are free to withdraw your information from the project at any point up until April 2nd 2021. You should note that your data may be used in the production of formal research**

outputs (e.g. journal articles, conference papers, theses and reports) and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study. To withdraw, please contact the lead researcher (contact details are also provided below). Please also contact the Research Supervisors (contact details are provided below) so that your request can be dealt with promptly in the event of the lead researcher's absence. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

What will happen if I decide to take part?

You will be asked to take part in an interview with the lead researcher using an agreed format (face to face, telephone or video link). **Due to the recent government restrictions and guidelines concerning COVID-19, face to face interviews will only be conducted if safe to do so.** You will be asked some open-ended questions about the research topic. The meeting should last no longer than 70 minutes. The interview will be recorded (and will require your consent for this).

Please note that in accordance with the research project design the researcher might want to contact you to interview you again. If this is the case, the researcher will contact you within two weeks of your original interview date. You can decide whether you would like to consent to this on the consent form.

The researcher would also like to receive feedback from you once the research is ready for submission. You can decide whether you would like to consent to this on the consent form.

What are the benefits of taking part?

By sharing your experiences, thoughts and insights with us, you will be helping the lead researcher and professionals working with young women to better understand how ED and DE is understood within this demographic. Young Black British women have been chosen in particular because of the under-representation in current eating disorder literature and you will be helping to give a voice to this group. This may help to inform future research and future clinical practice.

Are there any risks associated with taking part?

This study has been reviewed and approved through Coventry University's formal research ethics procedure and been approved.

However, it is recognised that talking about ED, DE and associated topics (i.e. body image) may be a sensitive subject for you. If your discussion becomes too difficult or distressing for you, you will be able to stop at any point during the interview either for a break or to withdraw if you wish to do so.

After the interview you will be given a chance to ask any questions and you will be talked through and given a debrief sheet detailing signposting information for your consideration.

We would always encourage participants to speak to their GP about support that may be available should the feel that this is appropriate. **There is the potential when discussing sensitive topics that a participant may disclose information that is concerning to the researcher. Depending on the nature of the information disclosed the researcher may have to breach confidentiality, including but not**

limited to the Research Supervisors (contact details are provided below). This decision will be discussed with the participant beforehand where appropriate.

Disclosure Protocol

In the event that a disclosure is made that is of concern to the researcher;

- the interview will be ended when safe to do so and the reason why will be explained.

- the researcher will make explicit to the participant that the information disclosed will have to be discussed with the Research Supervisors so that an action plan can be made.

- a Research Supervisor will be contacted as soon as safe to do so to discuss how to appropriately manage the disclosure.

- the participant will be contacted as soon as possible to feedback the action plan discussed.

Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential.

Signed consent forms will be kept in a locked cabinet separate from the interview data.

In the event of the interview being conducted via video link or telephone, consent forms will be provided via email for the participant to electronically sign or to be printed, signed and uploaded back to the lead researcher. Upon receipt, signed consent forms will be saved to Coventry University's online OneDrive as this is a secure location.

The original emails containing the signed consent forms will then be permanently deleted from the lead researcher's email folders.

Recordings will be made on a digital recorder or password protected computer. Recordings will be kept on Coventry University's online OneDrive. Afterwards the recording will be deleted. Once transferred the interviews will be typed up word for word (transcribed), removing all personal and identifying information and providing you with a made-up name (pseudonym). Once transcribed, the recording will be deleted from the OneDrive.

Any paper records will be stored in a locked filing cabinet at the University of Coventry. **These files will be kept by the University for 5 years after qualification and will be destroyed on or before 30.09.2026.**

Any quotes used for reports, conferences or written publication will be anonymised to ensure they are not identifiable.

The researcher will endeavour to take every precaution to keep participants anonymous but there may be a risk that you could be identified by phrases that you may use in your responses or experiences that you choose to share.

Data Protection Rights

Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will be anonymised in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

Making a Complaint (Contact Information)

If you are unhappy with any aspect of this research, please first contact the lead researcher;

Jacqui Kodjokuma

Doctorate Programme in Clinical Psychology

Charles Ward Building

Coventry University

CB1 5FB

kodjokuk@uni.coventry.ac.uk

If you still have concerns and wish to make a formal complaint, please contact a member of the Research Supervision Team;

Dr Carolyn Gordon

Academic Tutor

Doctorate Programme in Clinical Psychology

Charles Ward Building

Coventry University

CV1 5FB

02477658762

Dr Jo Kucharska

Clinical Director/Senior Lecturer

Clinical Psychology Doctorate Course

Charles Ward Building

Coventry University

CV1 5FB

02477658769

In your letter please provide information about the research project, specify the name of the researcher and detail the nature of your complaint using your participant number as a reference.

Appendix P. Informed Consent Form

Participant Identification Number:

PARTICIPANT INFORMED CONSENT FORM:

You are invited to take part in this research study for the purpose of collecting data on how **young Black British woman conceptualise (think about and understand) eating disorders and disordered eating.** You will be interviewed and asked questions in relation to eating disorders and disorder eating.

Name of Lead Researcher: **Jacqui Kodjokuma**

Before you decide to take part, you must **read the accompanying Participant Information Sheet.**

Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by circling YES against each of the below statements and then signing and dating the form as a participant.

1	**I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to consider the information presented and ask questions.**	**YES**	**NO**
2	**I understand that my participation is voluntary and that I am free to withdraw my data, without giving a reason, by contacting the lead researcher and the Research Support Office at any time up until 02.04.2021.**	**YES**	**NO**
3	**I have noted down my Participant Identification Number (top left of this Consent Form) which may be required by the lead researcher if I wish to withdraw from the study.**	**YES**	**NO**
4	**I understand that if I want to discuss my participation in this research any further or have any additional questions relating to the research, I can contact a member of the research team and the contact details can be found on the Participant Information Sheet.**	**YES**	**NO**
5	**I understand that relevant sections of data collected during this research may be looked at by members of the research team.**	**YES**	**NO**
6	**I understand that all the information I provide will be held securely and treated confidentially.**	**YES**	**NO**

7	**I consent to the information I provide to be used (anonymously) in academic papers and other formal research outputs i.e. journal publications.**	**YES**	**NO**
8	**I consent for the interview to be <u>conducted in the following formats:</u>**		
	Face to Face Interview	**YES**	**NO**
	Telephone Interview	**YES**	**NO**
	Video Link Interview (i.e. Zoom, Microsoft Teams or Skype)	**YES**	**NO**
9	**I consent to this interview to be recorded for transcription purposes.**	**YES**	**NO**
10	**I consent to the researcher contacting me within two weeks if a further interview is required.**	**YES**	**NO**
11	**I consent to the researcher contacting me again, for me to provide feedback when the research is ready for submission.**	**YES**	**NO**
12	**I agree to take part in the above study.**	**YES**	**NO**

Thank you for your participation in this study. Your help is very much appreciated.

Participant's Name	**Date**	**Signature**
Researcher	**Date**	**Signature**

Appendix Q. Participant Debrief Sheet

Participant Debrief

Thank you for taking part in this research project. We hope that you have found it interesting. The aim of the research project is to try and understand how young Black British women conceptualise eating disorders (ED) and disordered eating (DE). Gaining and insight into young Black British women's understanding, may have further implications for prevention and intervention strategies used in society.

Continued Support

If you feel upset by any of the issues discussed during the interview, and you would like additional support there are several ways in which you can access support. These are outlined below.

We would encourage you to also seek the advice of your local GP who can also signpost you to support services in your local area.

- **B-EAT (Beat Eating Disorders):**
  The UK's Eating Disorder Chartiy.
  https://www.beateatingdisorders.org.uk/support-services
  Studentline: 08088010811
  Helpline open 365 days a year 12pm-8pm Weekdays, 4pm-8pm weekends and bank holidays. One-to-one web chats available.
- **National Centre for Eating Disorders:** Everything you need to know about eating disorders treatment and information.
  https://eating-disorders.org.uk/
  Helpline: 08458382040
- **The Mix:** Information and Support Forum.
  https://www.themix.org.uk/mental-health/eating-disorders/eating-disorders-explained-5879.html
  Helpline: 08088010677
- **NHS:** Find Eating Disorder Support Services in your local area.
  https://www.nhs.uk/service-search/other-services/Eating%20disorder%20support/LocationSearch/341
- **The Tamarind Centre**: Providing a holistic health and wellbeing support service to BME communities in Coventry.
  http://tamarindcentre.co.uk/
- **IAPT**: (Improving Access to Psychological Therapy) service
  https://www.nhs.uk/service-search/find-a-psychological-therapies-service/
- **SANEline**: National out-of-hours mental health helpline offering specialist emotional support, guidance and information from 4.30-10.30pm 365 days a year.
  http://www.sane.org.uk/

Helpline: 0300 304 7000.

- **Big White Wall**: Online mental health community providing a full range of online support. https://www.bigwhitewall.co.uk/
- **Samaritans:** Samaritans work to make sure that there is always someone there for anyone that needs someone. 24 hours a day 365 days a year.
  https://www.samaritans.org/
  Helpline: 116 123

Within Your Institution

Most educational institutions have a dedicated **student support service**. They may be able to help support you and/or signpost you to further information and support in your local area.

Research Team Contact Details:

Lead Researcher: Jacqui Kodjokuma, Doctorate Programme in Clinical Psychology, Charles Ward Building, Coventry University, CV1 5FB, kodjokuk@coventry.ac.uk

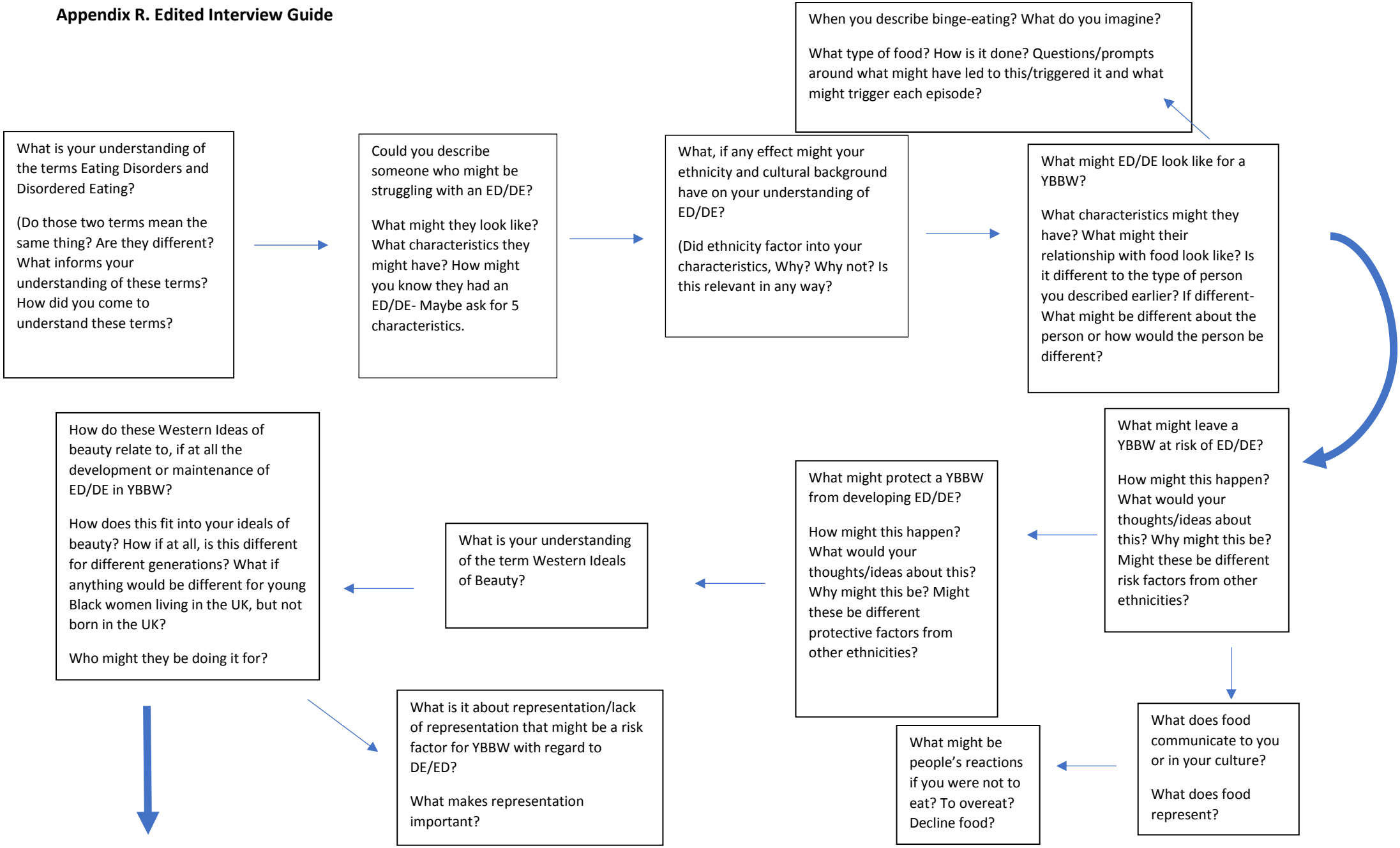
Research Supervisor: Dr Carolyn Gordon, Academic Tutor, Doctorate Programme in Clinical Psychology, Charles Ward Building, Coventry University, CV1 5FB. 02477658762

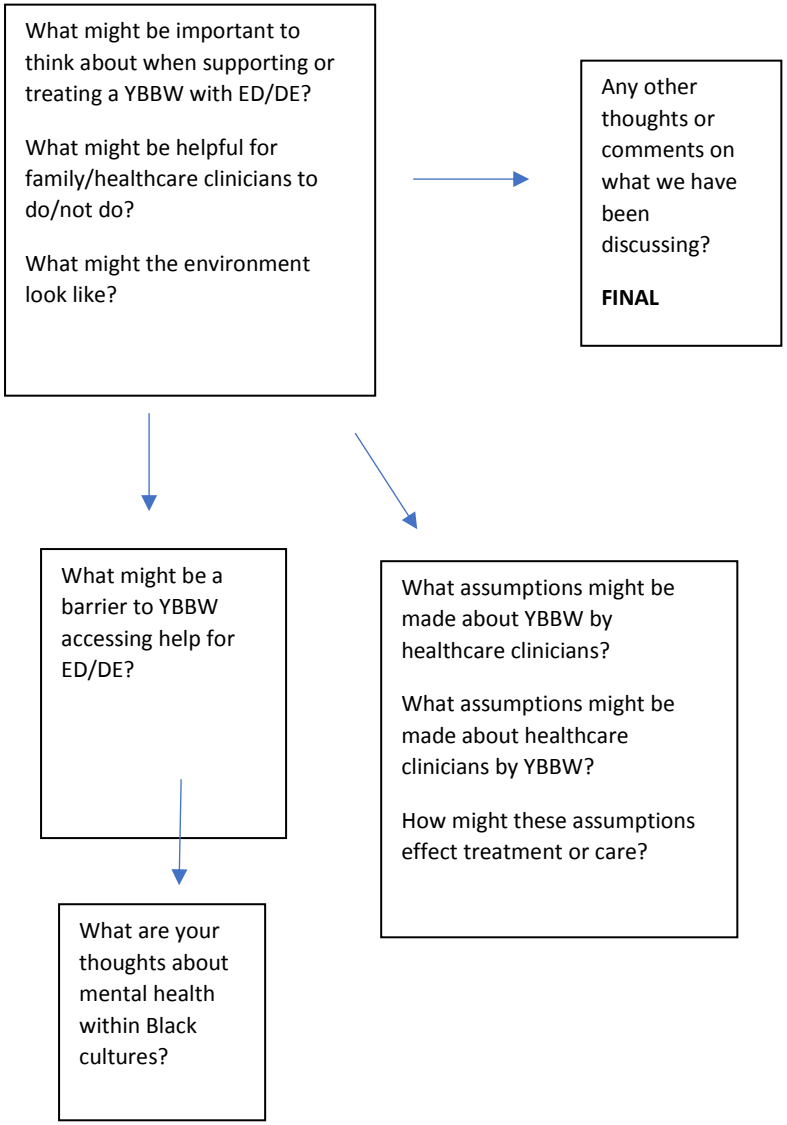
Research Supervisor: Dr Jo Kucharska, Clinical Director/Senior Lecturer, Doctorate Programme in Clinical Psychology, Charles Ward Building, Coventry University, CV1 5FB. 02477658769

We would like to take this opportunity to remind you that you have a right to withdraw from this research project should you change your mind. Please refer to your **Participant Information Sheet** to find out how.

Thank you again for your participation in this research project. Your time and contribution are greatly valued.

Appendix R. Edited Interview Guide





ED- Eating Disorders, **DE**- Disordered Eating, **YBBW**- Young Black British Women

Appendix S. Excerpt of Line by Line Coded Transcript

Focused Coding	I: What might leave a young Black British woman at risk of developing an eating disorder or disordered eating?	**Line by line Coding**
Neglect Marginalised Health services Stereotypes Accessibility Health inequalities Neglect Cultural Values? Vocabulary, Language, Discourse Stereotypes Perspectives/ Dialectic Cultural values- Faith	P: Erm, I also think neglect if I'm honest. And not just parental neglect but societal neglect. Erm, I genuinely believe that the plight, the emotions and the difficulties of Black women are considerably ignored by the majority of society. So, I'm talking about mental health services, things like CAMHS, erm, perhaps not necessarily capturing that demographic of people. Blaming those people for not accessing services and also having stereotypes about those people that prevents them from accessing services and getting the correct help. I'm thinking of hospitals as well, if you were to come in for something unrelated but someone was to notice you were significantly underweight, yeah alright, I think you would be more likely to receive treatment for that. Erm, whereas, I think even if you just look at other health inequalities for Black women there is evidence that indicates that there is just...I'm mean there is recent paper about it but there's a lot of work to be done in terms of how healthcare erm, really needs to step up to the plate. So, I can see how being neglected in that sense would mean that if you had an eating disorder it could go unnoticed or potentially unchecked. Erm, again, family attitudes and cultural perspectives about what looks like or what doesn't look like an eating disorder. Or even just having the cultural vocabulary for that. If I said eating disorder to my mum, she would just say *oh yeah so she's skinny*. Like my mum wouldn't necessarily think, you know, that the person spends hours thinking about how they look or controlling what they eat. My mum just thinks *oh she's a skinny person*. Erm, the idea that it's something that is....erm, in need of psychological or medical support isn't perhaps...what my parents and I can't speak for anyone else's parents...but I can imagine a vast majority of people might think the same way. Another thing that I think comes into it, which is very obscure, but I'm convinced....is erm...faith and religion. And the reason I say so is because I genuinely think ...and I'm sure it's not just Islam and Christianity but fasting can be a guise so obviously erm, in both there are periods of time where you fast	honesty, neglect, parental neglect, social neglect, society, emotions, ignored, difficulties, majority of society, mental health services, CAMHS, missed, blaming, stereotypes, prevent, barriers, accessing, right? correct help noticing, recognition, underweight, receive treatment, help, support, heath inequalities, Black women, evidence, recent, current, still work to be done, stepping up, "do better?" neglect, eating disorder unnoticed, unchecked, attitudes cultural perspective cultural lens? cultural vocabulary, conversation? skinny, simple? mother-generational, thoughts, factors? thought process? simplified? assumptions? Skinny support (mental and physical), generational, widespread, obscure, faith and religion, other faiths, fasting, piety, intimacy, normalised?

Relationships Masking/Visibility Education Discourse/ Conversation Visibility Representation Template Systems Invisible Visibility Marginalisation Extreme Nonentity Socioeconomic Marginalised Forgotten	for erm, piety or intimacy with whichever god you are serving, and I think if you are someone that has a tendency towards having a complicated relationship with food you can hide under that. Oh erm, intermittent fasting is the thing in society...but I have to fast because my religion says so, so that can definitely go unnoticed as well. Erm...what else? I don't know man, this life just comes for us, everything and anything can go. Lack of education. If it's not talked about you don't know about it, you don't think of it in that way. Erm, it's not something that even amongst my friends we've really spoken about until the last couple of years and that's because we all did psychology together. Outside that, they may not have the vocab or understanding or agree with the perspective. Erm, I guess the sense of erm...I guess what happened to me earlier, is us not being captured in people's minds. There's not template for Black women in the majority of other people's mindsets, unless you are one. And I am one and I still had that same kind of *oh eating disorder...yeah that's not us*. So, I think whether it's at higher level, in terms of like government, society, health systems...I think if it's out of mind...or out of sight it's out of mind, but also you can't really help who you don't think about. So, in that sense I think being forgotten, or not being understood or reflected about means that erm, we're marginalised in a way that is beyond the scope of the everyday person's understanding. It's not just about not having access, it's not about, not having money or being ignored or being abused. It's also about, just not existing in the minds of those who you might need to, in order to get the help that you need. I: [pause] thanks....and I suppose...you've given me quite a lot of risk factors...and I guess my question is might these risk factors be different for other ethnicities or races? P: Hmmm, so I guess when you phrase it as risk factors I also think of money. Erm, so I think of poverty, I think of...well right now the pandemic is showing us a lot of things...it's showing us the government clearly doesn't care about people that don't have food to eat, in this very Western Nation that supposedly "first world" in quotes. The term of which is an embarrassment to me, but anyway. The point being that if you are living in poverty, in fact, it was March this year a Black woman in, I think, London, starved to death. Correct?...	underlying proclivities? complicated relationship with food, intermittent fasting, trend? acceptable? unnoticed, missed, hard, education- lack, conversation-lack, awareness-lack, taboo? Not talked about, recognition? psychology, vocabulary, understanding, perspective, not held in mind, captured, template, missing, lost? lived experience, missing link? government, society, health, levels, invisible? unseen, unknown unknown, forgotten, reflected, understood, marginalised, beyond, empathy? accessibility, wealth, ignored, abused, not existing, risk factors, money, poverty, pandemic, context, government, neglect, food, lack, Western Nation, first world, embarrassing, poverty, recently, news, starved.

Appendix T. Selection of Memos

Memo: Poor diet- could this also be linked to socioeconomic status? Could this be to do with access to food and nutritional education. Language used is diet is poor rather than bad?	Memo: Skinny seems to be the universal indicator for an eating disorder. Recognition that it is not only someone being skinny that determines whether someone has an eating disorder but it's the most common indicator by which to judge someone- why is that? Does it have something to do with how eating disorders are portrayed?	Memo: Is there a lack of conversation because there is a lack of representation- People do not have the vocabulary to talk about eating disorders within their communities because nothing in the wider society alludes to the fact that this is a problem within the culture?	Memo: Mythical creature- sense that they (Black women with ED) might exist but never seen? So do they in fact exist?
Memo: Is that the feeling that might be pervasive when thinking about Black women within healthcare systems- more complex, more difficult. Language is never it is more nuanced, it presents differently etc. Just labelled as complex	Memo: Could that be a reason as to why Black women are more likely to suffer with binge-eating disorder- around food constantly but no desire to consume it?	Memo: Logically knowing that a Black woman could have an eating disorder but being unable to fit that into your knowledge and perceptions of eating disorders.	Memo: Food is central- gatherings are central and frequent- unpredictability could be due to impromptu gatherings, working schedules, childcare schedules etc.
Memo: Not knowing what to look out for? Not recognising any signs of difference? Is this because it is not on the radar at all as an issue let alone an issue that might be taking place in your own house?	Memo: Rejection of food is a rejection of affection?	Memo: Paradoxical- happy if you overeat but also will make comments on your weight.	Memo: Could argue that the beauty industry is a projection of white patriarchy.
Memo: More in recent years body positive movement. Understanding that it is not socially acceptable to make comments about weight/looks etc.	Memo: Comments about weight/looks/desirability still socially acceptable in different cultures- Juxtaposition with society that we live in today.	Memo: Characteristics described are almost opposite to "typically" Black features- tend to have wide noses, bigger lips. This could be why Black people without these typical features i.e. slimmer noses, lighter eyes, more Eurocentric features are often seen as "exotic" and maybe more praised for the proximity to whiteness.	Memo: School socialisation- group and group mentality- want to belong and be seen as the same as, increases pressure? Especially if you are a minority of a minority. Something about standing out twice?

Memo: Is there some shame associated with not having the same cultural experience or being different which translates into wanting to eliminate cultural ties?	Memo: Expectation that girls will want to grow up and marry and therefore need to be seen as desirable to a mate.	Memo: Important distinction between conversations and discussion.	Memo: If it is not discussed how it is supposed to be recognised. But how is it supposed to be discussed where there isn't the cultural understanding, narrative or vocabulary for discussions to be had.
Memo: Because it has to be really bad- YBBW might not recognise it within themselves until it reaches a critical point.			

Appendix U. **What might an eating disorder or disordered eating look like for a young black British woman? - Additional Quotes**

P001 *"Young Black British woman...erm...I feel like that would be probably towards the restricted eating. Erm...dieting...I don't know if this is a false perception but...comparing to primary school and thinking back. I feel like black women we do have different bodies...so you might not necessarily look so skinny. So, do you see what I'm trying to say...I'm not sure that makes sense but I've always known from primary school that my bodies a bit...more bigger...or thicker than a Caucasian person. Like ...so it not necessarily anorexia. So, I'd definitely say it would be more to do with dieting, restrictive eating that could...either...show up for a black person." 91*

"In the sense that because culturally especially...African foods are not as healthy...so eating yam or fufu or things like that is not necessarily the healthiest thing so already if you are struggling with an eating disorder you're going to feel like "okay I can't eat any" ...you might kind of push away your cultural foods." 102

"I say that because physically ...the majority of black women's body structure...just...it doesn't really get to the anorexia stage. Erm so...the difference I would say is body. Where it might not necessarily be looked at as skinny. The majority of black women I know they're not...you wouldn't get to that state of anorexia…You might not necessarily be able to tell. Unless they've just completely cut out food from their diet. I don't think our bodies can easily get to that state of...say a Caucasian person who suffers from anorexia" 109

P002 *"Erm, I'm not sure. I wouldn't...I wouldn't say I've ever imagined what that would look like. If I'm honest. I guess it would look like the same...if it was to happen to a Black British woman or a Black woman. I guess it would have the same look or for lack of a better word, same look or presentation that it would have on a white person. But it's not something that has ever crossed my mind..." 78*

"I would say they might have a poor relationship with food. Either they don't...they're trying to achieve a certain look and that's why they don't want to eat much food or they might be going through something else, like depression or anxiety and that's why they are overeating because there has been a change in their appetite." 83

"It's not that I don't think Black British women do not suffer from eating disorders. In my head it's not imagined that they are, that they do or they're not the faces that I see. Erm, so, I wouldn't say that there is something that is distinct that differentiates. I don't

think there is something where I think Black women don't have or do that makes them not have eating disorders if that makes sense? 96

P003 *"Erm...so it's interesting because I...I think perhaps...for a young Black British women I see them to perhaps suffer more with...I would perceive it...them to suffer more with...erm ...like binge-eating as opposed to something like anorexia or bulimia. And my reason for saying that is because like food is such a big thing for...in Black British culture and at least my experience is that it's not ...like...if you're at a family gathering and you're eating a lot of food that is not considered in any way a bad thing. Food is like seen as like a good thing and like you should eat loads and have more and you know. So I think it would be...I think it would be a lot easier for it to go unnoticed if it was like a binge-eating situation...I think if it was something like anorexia or bulimia where you're losing a lot of weight...I just...I mean...obviously it happens but I just think that it would be a lot harder to hide because...yeah because food is such a huge thing and I don't necessarily think that the whole culture of sort of dieting or like being...erm...overly controlling about what you do and don't eat...I don't think that applies that much in Black British families" 134*

"I think there might be an element of not understanding within themselves...because with a lot of mental illnesses there's...there's...I guess in its initial stages there's a lack of awareness about the fact that there is something going on. Erm...and it...it can often come quite late into the whole process, where that person has an actual awareness of what is happening to them. I think because there's not a lot of dialogue around it...I think in a...if you're a young Black British girl it might be quite easy to just attribute it to other things...erm...yeah I think there is a misconception that this sort of thing does not happen to Black women or you know...I think you would just attribute it to something else. Erm...I think that sort of...maybe...a complicated relationship with food would be just a symptom of like something else erm...rather than thinking oh no I actually have disordered...or...complicated relationship with food itself." 161

P004 *"…Maybe eating only certain foods, eating only at a certain time, erm if they're in school maybe not eating at school or eating a lot like the opposite. Erm...[pause] like having like...like overly like negative connotations to certain food groups. Erm...oh yeah! Also, because like if you're Black and British you also have like your food, what you eat and maybe not eating them...*

Does any kind of imagery pop up for you if I say young Black British woman...erm...and eating disorders?

[pause] No... nothing." 149

P005 *"If I go to either of my grandparents' house, the conversation of eating and what we're eating is very very very big. They won't be happy unless I have eaten. Erm, so I can imagine going into that environment and me having these...I guess negative thoughts about myself and my image and not wanting to eat, would just be a very frustrating environment to be in. They just wouldn't understand if I was struggling with thoughts about myself. Erm, and I think yeah it would just be trying to explain to them what's going on and them not just understanding it, would just cause a lot of frustration and you know...and that's when you get comments either way. You get comments if you're overweight, you get comments if you're underweight, without them actually understanding or asking what's going on or thinking...I think a lot of times people don't understand the connection with food and the mind. Erm, they don't understand how they're connected. So, yeah, I think it would be very difficult to get family or people from that culture to understand." 123*

P006 *"I think that...I think it can like be triggered by what some people say to you, especially like family members in our family. Starting from the church or something and then that can like trigger you into thinking oh like... are they really...are they correct in their thinking that I've put on some weight. You know and you start looking at yourself different and you try to do certain things that will help you reduce your weight and make those comments stop." 115*

"I'd probably say...I'd probably say like still obsessive in like the way they try to control their eating but erm, I feel like I'm painting like one worse, but they're probably like hiding it type of thing. Hard to articulate that. I feel like it's the same characteristics it's just that they hide it more." 122

P007 *"That is a very interesting question because I think Black people in Britain, we are quite diverse even within our Blackness. So, I would never compare my eating habits to a*

Jamaican person or a Ghanaian person or...and I assume...oh I guess I make assumptions that Black people are still like first generation or second gen, so they still eat what their families eat rather than eating just British food. But that's maybe based on my own experience, if I was to talk of myself or people I know, it might be erm... avoiding like social settings where eating is like a primary factor. Erm, if you were someone who was very concerned about becoming like overweight, maybe someone who perhaps is tending towards an anorexia type presentation, it might be erm...Often it's avoidance of carbs. I...and I don't know why I assume that, but a lot of people that I know that are Black and British that I feel like are disordered in their eating, they very much associate carbs with like being a bad thing. But, that's because a lot of like African food is carb heavy, whether it's like the Swallow or....wait, Swallow is not the right word...the stuff you eat with your hands that you have with like soups and stews. Erm...or whether it's rice erm often that's like the main part of the meal, so that there's this assumption maybe that if you eliminate that you can still eat healthily, and you can be slimmer. Erm...and I think a lot of lying and secrecy...I assume. I think as an ethnic minority we are already quite good at code switching, bringing multiple faces, presenting what is convenient in different environments. And so, therefore, erm...I almost think, and I hope you take this in the right way, that we'd be good at it. And that it would be easy to go undetected. Erm, unless you physically presented very, very very underweight. I think if you're overweight you'd probably just get mean comments from family, so I think there's...there's a massive amount of secrecy involved and erm...I can...I can maybe imagine the person not necessarily seeing it as an eating disorder. If I think of erm how a lot of aunties would be like "oh you're getting fat...why are you looking ugly now....do you not want a husband?" And anything you did to try and avoid being fat might be encouraged. So, perhaps, one that was unnoticed, unknown by the person themselves but kind of prompted by the family or the cultural context. Erm...yeah...I can't think of anything else off the top of my head." 222

"When they talk about women in the UK, erm despite being a Black woman, unless it's another Black person talking to me and they specifically say we're talking about Black people, then I don't consider us. Because, society doesn't tend to consider us. So my assumption is often you mean...Becky with the long brown hair…" 250

"There's almost the illusion in my head, despite me knowing it's completely problematic and wrong...that it doesn't apply. That...that erm Black people wouldn't have

an eating disorder even if I would identify what they're doing as disordered eating. It's almost like the difference in the term...you'd say a white person has an eating disorder and I might identify disordered eating in a Black person, but I struggle to look at a Black person and go "Oh that person has an eating disorder". Because, I think there is something about the schema or the way things are spoken about or presented or the lack of representation in that...that...that image is absent from my mind. Erm, I'd have to forcibly think "oh these are people I know, and these are the things I've seen therefore that is a Black woman with an eating disorder". But, that automatic image there...it's just not...it's not...it doesn't come up" 260

P008 *"I think...oh that's a good question." 110*

"For a Black British woman? I think it's a little bit more difficult. Because some of the foods that we eat can be very...eh...how do I say this. Let's say there are certain food that are like very rich in carbs if that makes sense, like really really heavy. So, if someone was to eat maybe one huge meal a day and snacks around it, I wouldn't necessarily say that there is anything too wrong with that. As opposed to, let's say if someone who was Caucasian only ate like one sandwich and snacks if that makes sense. Yeah, I think for a Black person it would be harder to tell, I think probably if they didn't eat much at all and they ate very little of everything, like their portions are really small...but I think if I'm being honest, I wouldn't know. It would be a lot harder for me to tell." 113

"I think our culture is centred around food a lot actually. So, we're always...girls especially are encouraged to always be in the kitchen making food and stuff. So, they might...so their relationship with food...I wouldn't necessarily say that they'd be scared of it because we're around it a lot and producing it a lot, but it would be more the fact that their...I don't really know how to put this into words. It's like the...the thing that entices you to food is not there. Making it but then they have no desire to consume it. A little bit like working in a factory where you're making something, and you're just making it because that's your job you don't actually want the thing that you're making." 126

"When I was describing someone generic, I wasn't actually thinking of a particular person. I guess the Black British girl could fit into that category, but it would be hard for me to imagine a Black British girl with an eating disorder. I know they exist but like I said

because it's not spoken about much and I don't see much of it, even when I see people maybe on social media talking about it, it's always white girls, it's never really Black girls. So, yeah it's hard for me to picture...it definitely exists but it's hard for me to picture myself." 138

P009 *"I feel like for most people it started off as like...maybe because during school it may have been the norm to skip meals. For me that was just not going to happen, but some people would skip major meals and then...there are foods say during school that people used to look at as like white people food or only white people really ate it. For example, like those rice cakes or ...erm mainly those rice cakes. So, girls would sit and bring like two of them for lunch and them just had that with water, take into consideration those people would have like PE or we had a lot of things to do during school. And then they would say skip breakfast as well so they're not really eating, and I think that would be a big contrast for Black girls because most of the time it's either you're first of all bringing like African foods or your making food or they would have more of a bulky lunch." 126*

"I feel like it would be really good to talk about their characteristics because most Black women that I come across are very good at hiding if they have an issue. So, we have to get really close to them to be able to see if they have issues. Maybe moments of extreme eating or if it's during a conversation and they would say...what have I heard...I feel like mainly just skipping meals. Characteristics would be...extreme tiredness...I would say that. Erm, refusing to eat certain things, I've come across...I've come across that. For example, like just not wanting to eat like the rice because they feel like that would make them gain more. Statements about their weight that...from an outside perspective just doesn't seem true. Some girls saying they're fat and I just...you wouldn't think that." 137

P010 *"So, it could be sort of things as simple as skipping meals, you know people doing the thing where they move their food around their plate to make it look like they're eating but really, they are on a diet. Also, I just think not...not...like eating too much and then purging or not even, eating just a little bit and still purging. It can look very different and sometimes you can't even see it. Erm...people develop habits of maybe always going to the bathroom after they've eaten and stuff like that because they are going to purge, or they've eaten a significantly larger amount of food because they're bingeing. So yeah, like*

it... it can be quite obvious but it's very easy to hide as well. Especially...I guess especially now that everyone's in lockdown and stuff...it might be even easier" 132

"I mean in where I've worked, I've not actually come across any Black women with disordered eating or eating disorders, they've all been sort of the typical like [inaudible] white women. I feel like...I personally think it could be the same for anyone but obviously there will be...I guess there will be cultural difference as well in the fact that ...I guess food is quit a big part of Black culture so it's probably harder to hide I suppose in like the meal eating sense of it. Because...yeah because you know when you have a gathering or a function it's like food is the main bit..." 142

P011 *"I mean I don't...I don't think it would necessarily look any different, but I think...I think potentially the body type that they're going for might be different...potentially...potentially not. I think so again it very much depends on your culture and kind of...and...and the cultural Blackness that you have. For example, a lot of...I guess a lot of Caribbean cooking and I guess a lot of West African cooking can use a lot of oil and you can become very very conscious of kind of oil and calories and things. And that's something that some members of your family are not going to get. They'll be like that's how we cook, that's how we've always cooked, that's how your mum and your grandma cooked, and everybody cooks, that's how it is. And I think it can be potentially more difficult to navigate. I guess something that may also be the case, and this is...I'm not trying to generalise at all...but this idea of I guess sitting and eating as a family or when people come over, you're having to kind of go downstairs and sit with them and speak to them and things and that's been a big thing in my family I guess...and I think it would be harder to not be scrutinized potentially for what you are, or you aren't eating and how you are, or you aren't with food. So, I don't necessarily...like I said I don't necessarily think it would look any different but the way that you...that a young Black British person may have to manoeuvre situations might be a little bit different potentially." 180*

"And I think even though eating disorders and disordered eating is about control, a lot of that control is about cultivating a shape that you think makes you feel more worthwhile or more attractive or yeah...more worthy of whatever thing you think you're not living up to. And I guess, those comments that I know my family definitely make and I think a lot of Caribbean people make, and I've had...kind of Nigerian men say the same

thing to me as well about body shape and body type and what's desirable, I think kind of also inform what you think you would want to look like or what you think a good amount of weight loss would look like on you. And I think that would make a difference in terms of what you're going for. So, how much you have in your bum or how much you have in your thighs versus your stomach so that kind of thing would be...would potentially be different?" 200

"I don't know and I guess the reason why I say I don't know is because I think...this might come out as like a contradiction to everything I just said but we've also live in a white society and the beauty standards that you see all the time are designed for white bodies or Black bodies on white women. And so, in spite of everything I've just said it might be that the body that they want is still that...it could still be that. And also, I guess with my understanding of disordered eating, which isn't expert level at all, but it is about that control and being able to restrict and being able to control what goes into your body and your amount of intake and being able to see how much you've eaten or how little you've eaten and the impact that that is having on you and I guess...that's very different to nutrition and if you're looking...if you've got into a habit of disordered eating or you have an eating disorder, I guess you're not going to be thinking about the balances of nutrients and the nutrition side of it. You're going to be thinking about restriction and the control, so I don't think you'd be able to make it look any different in how you were controlling you're eating necessarily because you wouldn't...that wouldn't be your mindset." 212

P012 *"I personally feel like it would have a lot to do with kind of trying to reach this desirable body image of Black womanhood. So, it kind of would maybe give you anxiety or the idea of over-eating or trying to diet and slim down to get this ideal body shape that is accepted and desired by others because I know Black women find it hard to find a space where we are seen as desirable. And I think a lot of that plays into that because we then see an image and we're like "oh she's desirable because she's got a flat stomach, big bum and big boobs, how do I get there? Do I need to under eat or overeat? Am I too skinny, am I too big?" And that idea of pressure, us being like that desirable image is the only way I can be seen as desirable as a Black woman, so I need to occupy that space and somehow informing our eating choices and what we eat. I know there is a lot of thing about people*

saying if you eat yard food then you can get a bigger bum and that type of stuff [laughs]. So, I feel like it all interferes with like our eating choices." 118

"I feel like sometimes...I feel like that pressure and that cultural aspect and that small frame of desirability that Black women and girls have to fit into isn't as small for white women or white passing women. They don't have that small gap to fit in. I think sometimes so much is interplayed on Black women's bodies and what it looks like as a point of entry in conversation and desirability for Black women that white women don't have. They have so many other things that are seen as desirable to them, that I don't think maybe their body type is as much as a pressureful situation as Black women. Yeah, so I feel like it's a different eating disorder because there are different background pressures and background entry points for an eating disorder." 131