

Women's experiences of disordered eating
across the weight spectrum in different contexts:
a scoping exercise.

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If we speak together, we can be heard. I dedicate this research to all people, across the weight spectrum, who have experienced disordered eating.

1 Abstract

Appearance-based judgements are common across a range of contexts but the utility of this in terms of health is questionable. Should the appearance of health take dominance over the reality of health, the consequences for the individual may be serious. Weight, as a source of stigma and discrimination, may be especially problematic in relation to appearance-based judgements and what follows, and individuals struggling with disordered eating may find it hard to gain recognition: this may well be mediated by weight. Recruiting individuals through an initial questionnaire, participants representative of the weight spectrum and age-range, were selected for interview. Phone interviews were semi-structured, exploring experiences of disordered eating and individuals' perceptions of the impact of their weight across a variety of contexts. The interviews were transcribed and uploaded to NVivo. Thematic analysis was then used to identify the themes and issues regarding weight presentation across the family, healthcare and social contexts. Clear evidence of weight-based bias within these contexts was displayed across the weight spectrum and suggestions for improvements were made regarding access to support and treatment, family support, and training for healthcare professionals and educators, with questions being raised around the assumed 'simplistic' connection between health and weight. In listening to the voices of those with lived-experience of disordered eating, we hear the clear message to not make assumptions about health based on weight and the request that we place greater emphasis on listening than on the appearance of health or functionality.

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Acknowledgements	1
1 Abstract	2
Forward.....	6
Index of abbreviations	8
A note on terminology	9
2 Introduction	10
2.1 Food, weight and life.....	10
2.1.1 Food: 'hidden' meanings	10
2.1.2 Weight and culture	12
2.1.3 The role of appearance in health care	14
2.1.4 Questioning assumptions and addressing complexity	17
2.2 Definitions and identification of EDs and obesity	18
2.2.1 Eating Disorders	18
2.2.2 Obesity	20
2.2.3 Disordered eating	22
2.2.4 Diagnosis	23
2.2.5 The challenges of defining and identifying disordered eating	25
2.3 The Costs:	25
2.3.1 Costs of Eating Disorders	25
2.3.2 Costs of obesity.....	25
2.4 The Models:.....	26
2.4.1 Models of EDs	26
2.4.2 Models of obesity	29
2.4.3 Acknowledging complexity in practice	30
2.5 The Treatments:.....	31
2.5.1 NICE Guidelines.....	31
2.5.2 NICE recommended treatments	32
2.5.3 NICE treatment goals	33
2.5.4 Treatment efficacy	34
2.5.5 Weight-based judgements?.....	35
2.6 Stigma (societal)	37
2.6.1 EDs	37
2.6.2 Obesity	37
2.7 Stigma (healthcare).....	38
2.7.1 Assumptions regarding EDs	38
2.7.2 Assumptions regarding obesity	39
2.7.3 Common assumptions regarding eating and weight-related health conditions.....	39
2.8 Is weight getting in the way?	39
2.8.1 The impact of assumptions based on weight	39
2.8.2 Exploring individuals' experiences.....	40
2.9 Research aims.....	41
3 Methodology.....	42
3.1 Quality assurance process	42
3.2 Research framework	43
3.2.1 Ontological assumptions.....	43
3.2.2 Epistemological assumptions.....	43
3.2.3 Methodology.....	44
3.3 Ethics and risk.....	45
3.3.1 Sensitive research	45
3.3.2 Risk assessment and management.....	46
3.4 Procedure	46
3.4.1 Recruitment	46

3.4.2	Sampling strategy	47
3.5	Analytic approach	49
3.5.1	Descriptive analysis.....	49
3.5.2	Qualitative analysis.....	49
4	Results	51
4.1	Questionnaire responses.....	51
4.1.1	Diagnostic complexity.....	52
4.2	Sampling across the weight spectrum	55
4.3	Qualitative analysis.....	56
4.3.1	Family.....	57
4.3.2	Healthcare.....	62
4.3.3	Social-formal	66
4.3.4	Social-informal	69
4.3.5	Self	71
4.3.6	Improvements.....	78
5	Discussion	82
5.1	Family.....	82
5.1.1	Weight and family.....	85
5.1.2	Family – summary and improvements	85
5.2	Healthcare	86
5.2.1	Weight and healthcare	88
5.2.2	Healthcare improvements	88
5.3	Social.....	90
5.3.1	Social formal	91
5.3.2	Social-informal themes.....	93
5.4	Self.....	94
5.5	Links to the literature.....	94
5.5.1	Food and identity.....	94
5.5.2	The role of the family.....	95
5.5.3	Visual indicators and the medical consult	95
5.5.4	Weight and identification of DE.....	95
5.5.5	Stigma – the assumption of control.....	96
5.6	Implications for theory.....	96
5.6.1	Models of Eating Disorders.....	96
5.6.2	Models of ED – summary.....	97
5.6.3	Models of obesity	98
5.6.4	Models of obesity - summary	98
5.6.5	Models of DE?.....	99
5.7	Returning to the research questions	99
5.8	Reflections on the research	101
5.8.1	Issues of quality	101
5.8.2	Researcher reflections	102
5.9	Future directions.....	103
6	Conclusion.....	104
7	References	105
8	Appendix.....	130
8.1	Systems map from Foresight report (Butland et al., 2007)	130
8.2	Social-Ecological Model	130
8.3	“Big-Tent” criteria	131
8.3.1	Worthy topic	131
8.3.2	Rich Rigour	132
8.3.3	Sincerity	132
8.3.4	Credibility.....	132

8.3.5	Resonance.....	133
8.3.6	Significant Contributions	133
8.3.7	Ethical.....	133
8.3.8	Meaningful coherence.....	134
8.4	Research audit trail	134
8.5	PPI.....	137
8.6	Risk assessment/ethics application.....	139
	Qualitative data	141
8.6.1	Risk assessment	147
8.7	Progression viva.....	149
8.7.1	Progression viva feedback	154
8.8	Online questionnaire.....	157
8.8.1	Questionnaire	157
8.8.2	Information sheet	161
8.8.3	Support lines	163
8.8.4	Debrief	163
8.8.5	Twitter promotion	164
8.8.6	Facebook promotion.....	164
8.8.7	Email to support groups.....	164
8.8.8	Promotion on B-eat Website, Facebook page.....	165
8.9	Interview schedule/framework and materials.....	165
8.9.1	Email sent to participants pre-interview	165
8.9.2	Interview verbal consent check.....	166
8.9.3	Interview schedule.....	166
8.9.4	Post-interview email	167
8.10	Descriptive analysis of each weight category	167
8.10.1	Weight categories: 'underweight'	167
8.10.2	Weight categories: Healthy weight	168
8.10.3	Weight categories: 'overweight'	169
8.10.4	Weight categories: Obese	170
8.11	Researcher's position	172
8.12	Complete list of treatments.....	173
8.13	Systematic Review	174

Forward

I enrolled on the Professional Doctorate in Health Psychology in February 2015. In the past three years, I have completed assessments across the five areas of competency laid out by the British Psychological Society:

Professional Skills in Health Psychology

Teaching and Training

Consultancy

Health Behaviour Change

Research

The University of the West of England have assessed and passed these modules and the marks have been verified.

The Research competency is assessed in two parts:

1. Systematic Review (appendix 8.13)
2. Thesis

My research interests lie in weight and health behaviour change. Having worked with patients diagnosed with Eating Disorders and individuals classed as 'obese' I had noted a clear distinction in the way that individuals living with obesity were perceived and treated both socially and within healthcare settings. The NICE guidelines regarding obesity focussed more on changing behaviour through modification of diet and exercise than in examining any potential underlying psychological factors (or biological factors in some instances). The 'obese population' appeared to be viewed as homogenous and the treatments offered routinely involved approaches with poor long-term outcomes. I queried the cost effectiveness of this approach for the healthcare system as well as the cost to individuals in terms of the consequence of a lack of success long term. Putting aside the complexity within the 'obese population', the health behaviour change required to move to and maintain a healthier weight at which there were less health implications was, I felt, best grounded within psychology and my systematic review examined the long-term efficacy of approaches that used standard lifestyle approaches (diet and exercise) in comparison with approaches that introduced a psychological component (e.g. CBT, Mindfulness, Motivational Interviewing, etc.). The outcome of this review was that

approaches that included a psychological component had better long-term outcomes but I also noted a lack of research regarding long term outcomes in this area.

There were clear barriers to longitudinal research around long-term outcomes for weight management programmes as part of a doctoral thesis so it was not possible for my research to follow directly from my systematic review. I had, across the course of the Masters and Doctorate programmes, gained significant clinical practice with more individuals diagnosed with Eating Disorders as well as individuals living with obesity and had noted that there was some crossover. Some individuals living with obesity were reporting symptoms of disordered eating but had been unable to gain recognition from HCPs; some individuals at a 'healthy weight' were also reporting symptoms of disordered eating and were also not gaining recognition from HCPs; some individuals struggled with a lack of acceptance of their eating disorder by friends as they "weren't skinny enough" and had been observed eating ("I've seen you eat – you don't have an eating disorder" – personal communications). Individuals presenting as 'underweight' were more likely to have their disordered eating recognised, their distress validated, and treatment offered. This seeming disparity was something that I felt warranted further investigation as disordered eating has health implications if not treated/addressed, regardless of weight. If this is an area where weight is preventing recognition of risky health related behaviours by Health Care Professionals (HCPs), then evidence of this would prove valuable.

The research would also speak to the general assumption on the part of the media and society that the 'obese population' are homogenous, as well as the assumption that an individual living with obesity is personally responsible for their condition. The latter assumption lies at the heart of weight stigma which constitutes a significant psychological burden affecting all aspects of life.

Although the research does not follow directly on from the systematic review, it does remain grounded within the research area of weight and health behaviour change in terms of focussing on individuals' treatment regarding disordered eating and establishing the response of HCPs.

Index of abbreviations

AN	Anorexia Nervosa
BED	Binge Eating Disorder
BMI	Body Mass Index
BN	Bulimia Nervosa
CAMHS	Child and Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
CRF	Cardio-Respiratory Fitness
DE	Disordered Eating
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, 5 th Edition
ED	Eating Disorder
EDNOS	Eating Disorder Not Otherwise Specified
GP	General Practitioner
HCP	Healthcare Professional
ICD-10	International Statistical Classification of Diseases and Related Health Problems manual, 10 th edition
MANTRA	The Maudsley Model of Anorexia Nervosa Treatment for Adults
MUS	Medically Unexplained Symptoms
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NSWS	Non-Standard Work Schedules
OFSED	Other Specified Feeding or Eating Disorder
PHE	Public Health England
PPS	Persistent Physical Symptoms
PSHE	Personal, Social and Health Education
PTSD	Post-Traumatic Stress Disorder
RCGP	Royal College of General Practitioners
RCP	Royal College of Physicians
SCOFF	Brief questionnaire assessing disordered eating (Sick, Control, One, Eat, Food)
SES	Socio-Economic Status
UFED	Unspecified Feeding or Eating Disorder

A note on terminology

This research examines weight, how it is perceived and the impacts on response across a range of contexts.

Although I refer to and use the Body Mass Index chart as a means of identifying and categorising individuals for the sake of this analysis, this should not be taken as an acceptance of its use as a simple means of categorising people regarding their health. Terms such as 'underweight', 'healthy weight', 'overweight' and 'obese' are used in reference to the categorisation system only and does not represent my condoning of the use of these terms in health consults or in general.

The concept of weight in terms of health is highly complex and cannot be simplified into four categories.

2 Introduction

“... the first and chief of our needs is the provision of food for existence and life.” Plato

2.1 Food, weight and life

2.1.1 Food: ‘hidden’ meanings

Food is essential to life. The maintenance of a nutritionally balanced diet, with a regular eating pattern has a strong connection to health and wellbeing, both physically and mentally (Rucklidge & Kaplan, 2016; van der Pols, 2018; Harbottle, 2011; Owen & Corfe, 2017; Stratton, 2007; Allison, 2000). However, in addition, as Ogden (2010) points out “...food communicates a sense of self, it acts as a medium of communication between individuals, and it is central to the establishment of a cultural identity.” (p65). There are connections to sexuality, our ‘worth’ within society, and our status. It also represents self-control. Our current cultural emphasis on dieting, arguably, equates ‘dieting’ with control, identifying this controlled-status as desirable socially and conveying approval on the act of dieting. Examining texts across the last four/five decades we see a shift in expectations around body size and the equating of ‘control’ with femininity: Garner et al. (1980) suggested a link between an increase in Eating Disorders (EDs - isolating anorexia for particular mention) with the cultural demands for thinner bodies; Bruch (1974) described individuals with anorexia as possessing an “...aura of special power and super human discipline”. Chrisler (2010) notes “...the importance of self-control to the performance of femininity.” (p608) but also points to the association between fat and illness as a root for assumption and stigma against larger bodies: “The notion that fat is bad is thus extended to the notion that fat is bad for you – and then, by further extension, that fat people themselves are bad.” (p610). Certainly, this particular association explains the stigma against ALL larger bodies but the particular association between control and femininity goes to the heart of why women with larger bodies are subject to greater discrimination and stigma than men (Fikkan & Rothblum, 2012) and there is no protection against such stigma and discrimination: “It is the last domain where anyone feels entitled to make a personal, pejorative remark without fear of censure.” (Beat, 2013). Sagay & Gruys (2010) also note the connection between weight presentation and judgement of character “...being heavy is seen as the embodiment of gluttony, sloth, and/or stupidity, while slenderness is taken as the embodiment of virtue. A deep-seated cultural belief in self-

reliance makes body size - like wealth - likely to be regarded as being under personal control and as reflecting one's moral fiber." (p232). How we 'use' food then, can be taken as an indication of who we are as a person and our 'worth'.

As a symbol of our cultural and religious identity, food-use conveys social status and power and serves a role in social interaction. Becut & Puerto (2017), examining the socio-cultural aspects of food, suggest that food and eating habits can be seen "... as an informative marker of social position through the life cycle, as well as a constituent component of social identity." (p2). With our eating habits "...regulated by social conventions and moral rules... food and social prestige are interrelated." (Becut & Puerto, 2017, p1), and the setting within which the food is consumed is part of this 'display' of status; as Johnston & Baumann (2007) point out "...cultural consumption sustains status distinctions." Food use can be seen as 'affective practices' (Parsons, 2015) that are socially constructed, emotional, embodied demonstrations of identity. What and how we use food is taken as an indicator of our status, with knowledge and use of 'good food' being a sign of 'high cultural capital' (Parsons, 2015); these links to identity may contribute to the challenges in changing eating behaviours (Jastran et al., 2009).

The family, as a 'transmitter' of identity and values, plays a role in the development of food-related behaviours. The differences in the way families across socioeconomic statuses (SES) converse about food (Fielding-Singh & Wang, 2017) provides some explanation for how dietary beliefs and behaviours develop differentially, and this can be seen in terms of a range of health inequalities observed across the SES range. Neumark-Sztainer et al. (2008) noted an association between frequency of family meals and disordered eating (DE), higher frequency serving as a protective factor, with individuals less likely to engage in 'extreme weight control behaviours'. The parental style as well as the routines around meals were identified as key factors in the development of healthy eating habits (Fiese & Bost, 2016), and the role of food as a means of conveying love and concern or to 'pacify' children has also been discussed (Lawrence, 1984; Charles & Kerr, 1987). Hamburg et al. (2014) discuss the interpersonal importance of offering and accepting food - between parent and child it serves as a 'bio-behavioural regulatory interaction' which can increase positive affect in both recipient and provider but can also increase interpersonal closeness in general. From a developmental perspective, should the provision of food *replace* support behaviours, food may be seen as a key/main means of soothing; as a coping behaviour.

Although food is fundamental to life, the “first and chief of all our needs”, the role of food is highly complex; it provides a ‘snapshot’ of our identity on which assumptions and judgements of our ‘worth’ are made. Food connects with morality, religion, culture, health, socioeconomic status, identity, femininity, body size; it plays a role in social situations, celebrations, life events, within relationships; and our food use (or assumed food use) is taken as a public demonstration of our worth as individuals. Simplistically, how we ‘appear’ takes dominance and directs judgements and assumptions of health and worth. The complexity around food and its connection to health presents as a subject of interest for Health Psychologists particularly, with a foundation in the biopsychosocial approach, situating health in the broader social, cultural and economic contexts. Considering multiple influences and factors to provide a contextualised and nuanced understanding of food, body size and the links to health enables us to reach beyond the ‘snapshot’, facilitating an informed refinement of our approaches to the associated challenges and health issues.

2.1.2 Weight and culture

We all make assumptions based on appearance; this is nothing new. But how we judge peoples’ weight has changed over the years. Prior to the agricultural and industrial revolutions in western civilisations, thinness was equated with illness and poverty whereas ‘plumpness’ was a sign of wealth and health (Klein, 1996; Stearns, 1997; Brown & Konner, 1987; Ember et al., 2005). As consumerism grew from the early twentieth century onwards, this judgement reversed: “An appropriately slender figure could denote the kind of firm character, capable of self-control, that one would seek in a good worker in an age of growing indulgence; ready employability and weight management could be conflated” (Stearns, 1997, p59-60). Weight began to be seen as a yardstick for good character in cultures with strong beliefs in the importance of self-reliance, holding sway in terms of moral judgements. Parsons (2015) states that how we use food in our current cultural environment allows us to ‘present’ ourselves as responsible citizens and “...demonstrates an engagement with public and medical discourses that position the self as responsible for her or his own health and well-being (responsible individualism).” (p1). Weight then, becomes conflated with morality.

How the media reports on issues regarding weight is a key driver and perpetuator of opinion. Without the ethical and scientific framework required for all published research, news agencies and general media, with their far-reaching distribution and impact

potential, are in a position to lead opinion. This can become a disruptive element when reports are made which do not represent current scientific knowledge (Bombak, 2014); examples of news reporting of unpublished (hence non-peer-reviewed) studies are not uncommon (Mundasad, 2017). Saguy & Almeling (2008) found a narrative of blame prevalent in news reports on scientific findings, a narrative that was not present in the findings themselves and Boero (2007) found that a frame of morality issues, gluttony and sloth tended to be present in news reporting around obesity. Media handling is important: 'bad science', or even simply celebrity opinion, can be promoted in a 'factual' way that can be both misleading and toxic, amplifying moral judgements and assumption through sensationalist reporting.

An examination of media handling of different weight presentations in the United States indicated that individuals with anorexia were portrayed as "...victims of a terrible illness beyond their and their parents' control..." (Saguy & Gruys, 2010, p232) whereas obesity was portrayed as being "...caused by bad individual behaviour, including, in the case of children, parental neglect." (Saguy & Gruys, 2010, p232), reinforcing "...moral hierarchies based on body size..." (p232). Such representations are unhelpful: for individuals battling EDs, it suggests a disempowerment that undermines the potential for and process of recovery; for individuals living with obesity it negates the fuller scientific understanding of the complex causes of obesity, suggesting instead a narrative of personal responsibility and poor moral character, reinforcing the 'snapshot' judgements around 'responsible citizenship' (Parsons, 2015).

Our current environment is often referred to as 'obesogenic' (Butland et al. (Foresight), 2007; Swinburn & Egger, 2002); food in plentiful supply, abundance of cheap, high calorie, highly palatable foods, technological advancements requiring less physical work to maintain the daily tasks of living, and low pressure to be physically active. Within this context, hunger, the drive to eat, can be easily subverted by issues such as stress, emotion regulation, comfort, boredom, etc. (e.g. Torres & Nowson, 2007; Groesz et al., 2012; Crockett et al., 2015; Dallman et al., 2005; Dube et al., 2005; Triosi et al., 2015; Triosi & Wright, 2017; Costa & Brody, 2013). Arguably, a lack of successful adaptation to our current environment has led to what is felt by many to be an 'obesity pandemic': "Obesity is the result of people responding normally to the obesogenic environment they find themselves in." (Swinburn et al., 2011, p.804). From an evolutionary perspective, there are a number of suggestions for this 'pandemic' (the 'thrifty' gene, the 'drifty' gene and the theory that genes were selected on the basis of the need for thermo-regulation

within different climates, Sellayah et al., 2014). That there is a genetic component is agreed, but that the causes of obesity are complex and multifactorial, being influenced by many social, food and physical environmental factors, has also been established (Foresight, 2007): we understand that there are complex biopsychosocial origins to this issue.

Our weight presentation demonstrates our standing socio-culturally as citizens (Parsons, 2015) with a 'controlled' body size denoting 'firm character' and social desirability, and larger bodies indicating less control, the individual being judged 'less' in many ways. Although there is much discussion about the 'thin-ideal' (i.e. Stice, 1994; Vander Wal & Thelen, 2000; Halliwell & Harvey, 2006), in reality there is somewhat of a 'Goldilocks phenomena': you can be 'too fat', you can be 'too thin', and both of these are 'wrong' bodies - what you 'should' want to be is 'just right' because that demonstrates worth, value and 'responsible citizenship'. But at any weight there might be struggles, socially, physically or mentally, because weight does not provide and cannot be taken as a simple indicator of character, intelligence, ability, moral standing or health. With the media reinforcing simplistic assumptions around health and body size we are distracted from the complexity around weight. We need to explore that complexity in order to better support the health and wellbeing of individuals, but appearance would seem to stand in the way.

2.1.3 The role of appearance in health care

There are some visual clues that can reasonably be used in a health consult as potential indicators of underlying disease (e.g. clubbing of fingernails, pallour, jaundice, rashes, bulging eyes, rosy cheeks) or can be indicative of underlying psychological distress (i.e. issues with eye-contact, self-care, various behavioural indicators) but appearance is not a clear indicator of health. The pull to appearance is strong though, with deep roots in the idea of a 'standard' or 'average' that has infiltrated into the medical arena.

This idea originates in the philosophy of Pythagorus and Plato, whereby mathematics was deemed to be a model for perfection. For subsequent philosophers, things that were distinct, measurable, and in 'proportion' were seen to hold moral and aesthetic worth and, conversely, those without to be lacking in moral value (Stafford et al., 1989). By the fifth century, this thinking was brought to human physiology (Proclus), attaching moral character types to physiological taxonomy. This 'quantification' of nature connected outer beauty to inward morality within physiognomic theory in the eighteenth century:

lacking in geometrical proportionality, 'disorderly' features were not valued aesthetically and were taken as indications of an inner and ethical 'wrongness'. This approach proved popular: Lavater interpreted 'deviations' in appearance as symptoms of underlying deviation (*Essays in Physiognomy*, 1775 – 1778); Camper (Gould, 1981; Grindle, 1997) determined cultural superiority on the basis of mathematical regularity. These works then formed a basis for the phrenological theories of the late eighteenth and early nineteenth century (Gall, 1758 – 1828; Spurzheim, 1776 – 1832) whereby, through the use of callipers and craniometers, measurements were used to determine intellectual ability, potential and moral worth. Although these ideas were dominant and popular, there were countering arguments, notably Lichtenberg (1778) who argued that the passage of time itself causes alteration in appearance but not necessarily one's abilities or moral value. The idea that beauty and regularity confer morality and value, however, is pervasive: "Very seldom [doth] an ill soule dwell in a beautifull bodie. And therefore is the outward beautie a true signe of the inward goodnesse" (Castiglione, 1561, p.309).

Across time there appears to be an incessant desire for simplicity and predictability where complexity exists, a desire to be able to predict values and abilities on appearance where this is not practically possible, a desire to know more on the basis of little - to judge someone on the basis of how they look: "everything in nature brings a distinctive or hieroglyphic sign to the surface by which observers can easily recognize secret virtues and properties." (Pernety, 1843).

Medical professionals cannot be held as immune to the tendency to want to judge on the basis of appearance; Jutel & Buetow, (2007), note the ubiquitous issue of judging health on appearance by both the lay and the professional alike. Spitzack (1990) suggests that culturally determined standards of appearance replace standards of health (i.e. the 'ideal' muscular form of the male and the 'ideal' slender form of the female). Within Western society, the pressure to achieve these ideals can lead to a neglect of actual health-protecting and health-promoting behaviours - the image of health replacing the reality of health. Among medical professionals there is also a response to individuals not meeting the 'standard' that can, if not noted and made conscious, impact on the care provided (Stafford et al., 1989); overvaluing of appearance within the consult serves as a barrier, or to mislead. It is important to note the power that comes with medical opinion: "The prestige of any proposal is immensely enhanced, if not justified, when it is expressed in the idiom of medical science." (Zola, 1971, p496). When we align appearance with illness, backed-up with the power and status of the medic/HCP, the pressure becomes intense.

Taking Foucault's (1973) description of the medical consult as 'the active eye and the mute body', the issue of weight presentation becomes evidently problematic in a culture where fat is bad, with problems arising for individuals at all weight presentations.

Although there is contention around the 'fat and fit' concept, and there is clear evidence that too much body fat does increase the risk of a number of health conditions (i.e., Poirier et al., 2006; Aune et al., 2016; Sharma & Lau, 2013; WHO, 2018; Pottie et al., 2006; Shu-Zhong et al., 2016), there is also evidence that individuals who are overweight that have healthy diets and regular exercise have lower health risks than 'thin' individuals who do not (Buetow & Docherty, 2005; Gaesser 1999; Lee et al., 1999; Nevill et al., 2006).

There is an emphasis on the need to maintain within the 'healthy body mass index range' – for the body to appear to conform - with a publicly accepted view that diets are the way to achieve a 'healthy weight' (forming part of the National Institute for Clinical Excellence's guidance on weight management, NICE, 2014).

Various researchers have attempted, on the basis of a lack of positive long-term outcomes for the dieting approach with its emphasis on reducing weight, that new directions should be sought, based around health, in order to protect the public from the dangers of dieting and weight-loss pharmacology (Cogan, 2002; Ernsberger & Koletsky, 2002; Cogan & Ernsberger, 1999). The public health emphasis on dieting and weight-loss has also been queried: Austen (1999) points to the problematic emphasis on dieting and body management and the direct links to DE, where public health bodies appear to see the two as unrelated, thereby supporting the industries and markets around diets; and Hesse-Biber et al. (2006) suggest that the economic and social institutions that promote the "cult of thinness" are, effectively, promoting DE. A focus on weight can easily distract from the more appropriate focus on health. The message of health gets lost in the messages around obesity and weight: the overweight are directed to lose weight; those at 'healthy' weight don't tend to have their diet and exercise patterns routinely queried; the 'underweight' are not automatically scrutinised. What is clear, is that at greater weights, there is greater negativity (Hebl & Xu, 2001; Kreuter et al., 1997; Puhl & Brownell, 2003; Garcia et al., 2016; Phelan et al., 2015; Obesity Action Coalition, 2018; Lindhardt et al., 2013).

That weight is used as a 'screening tool', determining how a HCP responds, what diagnoses are considered, what advice or treatment is provided, is also evident (Jutel & Buetow, 2007). Kreuter et al. (1997) point to the "...quick but fallible heuristics that systematically exclude patients whose needs are not easily visible" (p825) as a key factor

in determining which patients get what advice; weight is a visible indicator that is used in these 'fallible heuristics'. Walsh et al. (2000) suggest that a patient with bulimia nervosa (BN) may be missed when they present at either a 'healthy' or 'overweight' status, and it is not just the 'healthy' and 'overweight' who are at risk of not having DE identified. There is a notably higher use of health care in primary settings for individuals who self-report DE (and go on to receive an ED diagnosis, Sansome et al., 1997; Ogg et al., 1997) and there is evidence to suggest that HCPs in primary care settings are not taking these opportunities to ask relevant screening questions (Johnston et al., 2007; Boule et al., 2002; Stevens et al., 1999). Beat's (2017) report found that many individuals visited their GP (General Practitioner) on multiple occasions before being referred for specialist treatment; the number and length of delays in receiving treatment are noted as being especially problematic for individuals with DE. Beat detailed the commonly reported 'misunderstandings' that GPs may have around EDs and DE: that the duration of the problem isn't significant, that the weight presentation does not indicate a referral is necessary or that the individual is 'going through a phase'. Although a potential lack of misunderstanding on the GPs part was refuted by the Royal College of General Practitioners (RCGP, 2017) the experiences of patients and their families/carers does suggest that there are issues around recognition for DE and that weight is part of these issues. In a healthcare environment that increasingly values and requires the voice of the patient to be heard and responded to, we are obligated to take note of and respond to such reports.

2.1.4 Questioning assumptions and addressing complexity

The conflation of weight and morality has deep roots historically, philosophically, culturally. Weight presentation leads to assumptions around character, behaviour and health, directing judgements; the appearance of health routinely taken as proof of health. This creates immense social pressure around body size, directing individuals to take actions to 'correct' their appearance by means that do not support their health in the short, medium or long-term, arguably providing an environment that inclines individuals towards disordered eating. Although the relationship between food, weight and health is complex, we frame issues around this in very particular ways, as either a 'mental health' issue or a 'moral failing' – the latter framing those whose weight presentation lies above a defined 'healthy range'; and those who present within the 'healthy' weight range are assumed to be healthy. With knowledge that the relationship between food, body size

and health is complex, that issues around 'overweight' are increasing and the response to obesity and disordered eating is often unhelpful, these assumptions require examination, starting with a review of our current understanding of disordered eating and weight-related issues.

2.2 Definitions and identification of EDs and obesity

2.2.1 Eating Disorders

Eating Disorders (EDs) are largely seen as originating within the self as a result of a complex combination of factors including social and family dynamics (Treasure & Schmidt, 2013; Stice, 1994). In addition to the psychological and emotional impacts, there are physical health risks. It is worth some examination of the individual diagnoses as some of the issues around accessing and receiving treatment are noted to originate in issues around perception and accurate diagnosis (Beat, 2017). A gender bias with males constituting only 11% of sufferers, should also be noted, Beat, 2018).

EDs are defined by the diagnostic criteria within the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition: DSM-V (DSM-V, 2013) and the International Statistical Classification of Diseases and Related Health Problems manual, 10th edition (ICD-10, 2010). The different diagnoses are: Anorexia Nervosa (AN); Bulimia Nervosa (BN); Binge Eating Disorder (BED); Pica; Rumination Disorder; Avoidant/Restrictive Food Intake Disorder (ARFID); Other Specified Feeding or Eating Disorder (OSFED); and Unspecified Feeding or Eating Disorder (UFED) (DSM-V, 2013). BED was a new addition to DSM-V, the previous diagnosis of Eating Disorder Not Otherwise Specified (EDNOS) being removed to make way for a more accurate diagnosis for those who fell outside the diagnostic criteria for AN or BN.

Anorexia nervosa is, arguably, most well-known. It tends to attract more media attention and is noted as the psychiatric illness with the highest mortality rate, (Birmingham et al., 2005). Individuals with AN can look very unwell. It is, though, the ED with the lowest prevalence (0.1%, in the general population (Dovey, 2010); prior to the change in diagnostic criteria, Beat (2018) estimates 10% of individuals with an ED have an AN diagnosis). The diagnostic criteria for AN are very strict - individuals need to meet all the criteria in order to receive the diagnosis, one of which is 'significantly low body weight'. There is some debate over what this means but the cut-off point of the lowest end of the 'healthy' BMI range (18.5) is commonly used. This is problematic as many of the

additional physical health impacts of restriction (e.g. bradycardia, issues with organ function, amenorrhea, hair loss) can occur without reaching this BMI. There is a commonly held perception that AN impacts exclusively on middle-class young white females however this is also inaccurate (males constitute as much as 25% in the age range 8-14 although outside of this age range the rates are much lower (Beat, 2018) and rates in the region of 0.56% are estimated in China (Huon et al., 2002)).

Bulimia nervosa was first identified around the late 1970s/early 1980s. It is hard to establish true prevalence rates as the behaviours around this disorder are more easily hidden (unlike the dramatic weight-loss of some individuals with AN) however an estimate of 1-3% is suggested (general population, Dovey, 2010) and Beat (2018) estimate that around 40% of individuals with an ED meet the criteria for BN. The eating patterns for individuals with BN tend to be chaotic, involve bingeing and purging (in various forms) and there can be an 'over-evaluation' of the importance of weight/shape. Individuals with BN vary in weight presentation with many individuals presenting at a 'healthy' or 'overweight' status.

Binge Eating Disorder's prevalence is not well-known (as a new addition to the DSM), with rates of 3% suggested within the general population (Lilenfield et al., 2008), and estimates between 7 and 46% for those seeking weight-loss treatment (Williamson et al., 2004; Gluck et al., 2004). The gender bias within this group is less (1.5:1 females to males) and there are no noted ethnicity biases. Obesity is common in individuals with BED and many individuals are noted as having previously met criteria for BN.

OFSED and UFED, also new to the DSM-5, have less prevalence data available. Beat (2018) estimate that 50% of individuals with an ED fall across OFSED, UFED and BED and in 2016 Mustelin et al. estimated 21% of ED sufferers met criteria of OFSED/UFED with two thirds of this group falling under the UFED category. However, we need more research to determine true prevalence; persistent issues of secrecy and stigma act as barriers to this.

2.2.1.1 EDs and diagnostic migration

Despite the clear diagnostic criteria, EDs are not easily identified and diagnoses can change within one individual across time, with 'diagnostic migration' being common (Fairburn, 2013, p32). This is particularly problematic where treatment is diagnosis-specific, i.e. approaches which target binge-eating behaviours may be triggering for individuals who have previously experienced AN; and individuals who are 'sub-threshold' may fall into a 'diagnostic/treatment limbo'.

These issues present as problematic for healthcare and the individual alike.

2.2.1.2 EDs and weight-presentation

The appearance and weight-presentation of individuals with an ED can vary. The behaviours prevalent among individuals with EDs can be hidden and/or masked with secrecy, being noted as a barrier to identification of any issue in this regard. For example, an individual with BN can maintain in a 'healthy' weight range, AN makes up approximately 10% of cases of ED and not all individuals with AN present at an extreme low weight, individuals can struggle with binge-eating, extreme restriction and purging behaviours at any weight. Weight presentation then, is an unhelpful indicator in the majority of cases of EDs.

2.2.2 Obesity

Obesity is defined primarily by BMI status. There are different degrees of obesity (NICE 2014): BMI 30-34.9 – Obesity I, BMI 35-39.9 – Obesity II, BMI 40 or more – Obesity III. Waist circumference is also considered (NICE (2014) uses three categories of waist circumference). Associated risk is assigned to the differing combinations of obesity, waist circumference and the presence of comorbidities which align with a recommended 'tier' of intervention (diagnostic/treatment link, see section 2.5). Obesity is associated with various comorbidities in physical health (e.g. diabetes, hypertension, cardiovascular diseases, osteoarthritis, certain cancers (World Health Organisation, (WHO) 2018)) and mental health (e.g. anxiety, depression (Kasen et al., 2008; Carpiniello et al. 2009; Rosenbaum & White, 2013; de Man Lapidoth & von Hausswolff-Juhlin, 2014; von Ranson et al., 2011; Riva et al., 1998; Pinna et al. 2011)).

The overly simplistic nature of BMI as a measure is noted (NICE, 2014) and caution is advised when assessing athletes in particular. There is some debate regarding changing the way we assess obesity, notably Sharma (2017), who suggests that BMI is a good measure of size but not health. He suggests conducting a thorough clinical assessment, taking into account "...mental and physical health as well as overall well-being for issues that may be directly caused (or aggravated by) the presence of abnormal or excess body fat.", whilst noting that determining 'abnormal' or 'excess' body fat would need to be established as well as the relationship between body fat and health impairments. This would, Sharma feels, better inform treatment or intervention choices, and eliminate the blunt tool of the "arbitrary BMI cut-off", that provides little in terms of clinical detail.

Studies suggest that improvements in cardiorespiratory fitness attenuate clinical risk in adults and children living with obesity (e.g. Do et al., 2018; Nystrom et al., 2017) which underlines Sharma's point regarding the need for a more detailed clinical picture in order to more accurately assess health and risk for individuals living with obesity.

The rates of overweight and obesity are rising with an associated increase in healthcare costs. Obesity prevalence increased by 15% between 1993 and 2015; in 2015, 58% of women and 68% of men were classified as overweight or obese (NHS Digital, 2017). Rates of obesity in children are also high: in 2015/2016, >1 in 5 reception children and >1 in 3 children in year 6 were classified as either overweight or obese (NHS Digital, 2017). Rates of obesity specifically are predicted to rise to 46% of men and 40% of women by 2035, with associated rises in obesity-attributable disease (diabetes, coronary heart disease and strokes, Wang et al., 2011).

It is also notable that there are higher levels of obesity among individuals with other mental health diagnoses, first documented more than 7 decades ago (Nicholson, 1946), with a 2-3 fold increased risk of obesity for individuals with mental illness (Avila et al., 2015), and notable increased risks of obesity for individuals with ADHD (attention deficit hyperactivity disorder), PTSD (post-traumatic stress disorder), mood disorders, schizophrenia, substance abuse and binge disorders, although the links are not well understood and the influence of medications with weight-gain side-effects is unclear. There are also clear links between obesity and socioeconomic status (SES, Public Health England, (PHE) 2014), making obesity an issue in terms of health inequalities. Obesity, then, is defined in highly simplistic terms which belie the variety within the patient population and a highly complex aetiological picture.

2.2.2.1 The complexity underlying obesity

The pressure to find ways of addressing overweight and obesity that are effective is growing with the increasing rates of obesity and overweight. However, we do not yet fully understand all the mechanisms whereby obesity impacts on health; the clinical picture regarding health and risk in individuals living with obesity is complex; there is a complex relationship between weight and mental health; socioeconomic status is related to weight, with obesity presenting as a health inequality. There is a strong argument to be made for addressing these complexities if we are to find effective means of reducing the health impacts of obesity.

2.2.3 Disordered eating

It is important to distinguish between EDs and disordered eating (DE) as only the former is a diagnosis which triggers care pathways within the healthcare system. There are health implications to DE however: the direct impact of malnutrition on attainment or maintenance of body composition as well as physiologic function should not be ignored (Jensen et al., 2013; Mauldin & O-Leary-Kelley, 2015) as there are costs to the individual's health and wellbeing, as well as costs to the healthcare system. DE can also lead to obesity and/or an ED.

DE can be defined as any behaviours that disturb a healthy eating pattern. This can include restrictive practices, diets that exclude major food groups, bingeing, purging, missing meals, using frequent meal substitution, excessive exercise used for weight control, other extreme weight control practices and disruptions to healthy eating - behaviours that you might find in an individual with an ED but without reaching the 'clinical significance' of diagnostic status.

With an emphasis on appearance, the societal pressures to meet a 'healthy weight' and a condoning of diet-culture, which arguably promotes DE, it is little surprise that DE has become an important and common issue in society today (Neumark-Sztainier et al., 2012; Sim et al., 2013).

2.2.3.1 DE, health and weight presentation

DE's prevalence is challenging to estimate, partly due to the secrecy associated with these behaviours but also because many disordered eating behaviours are included in 'crash' and 'fad' diets (which are viewed as socially acceptable). DE appears to be common however among both children and adults at 'over' and 'obese' weight presentations (i.e. Nagata et al., 2018; Goldschmidt et al., 2008; Hayes et al., 2018) as well as in individuals with certain health conditions with dietary implications (e.g. Type 1 diabetes and Coeliac disease, Latzer et al., 2018). Individuals with ED symptoms not meeting 'clinical significance' can vary across the weight spectrum with many individuals maintaining weight rather than fluctuating. With the prevalence of DE among higher weights, true rates of DE could be alarmingly high. The potential health implications for this should not be minimised.

2.2.4 Diagnosis

Our healthcare system relies on diagnostic-led pathways to ration and direct care. Treatments are typically accessible on receipt of a diagnosis and are often diagnosis-specific. This places significant reliance on diagnosis, its process and its meaning in terms of health; this requires detailed examination.

For the patient, diagnosis serves a number of purposes – it can create clarity (or confusion), empower (or crush), enable (or create a feeling of helplessness). As Jutel (2011) notes: “The power of diagnosis is remarkable”. In terms of healthcare, diagnosis is a tool that aids understanding, is a means of communicating a large amount of information efficiently between practitioners (Davis, 2010; APA, 2000), and activates treatment pathways, serving as a gateway to treatment. This creates issues for individuals who are sub-threshold diagnostically: Krueger & Eaton (2015) point out that “...sub-threshold disorder manifestations can be associated with significant distress and dysfunction” (p.27). They further point out that individuals with the same diagnosis may have different degrees of severity which brings into question the boundaries of the diagnoses themselves. It is also not uncommon for HCPs to disagree on diagnosis. If diagnostic clarity cannot be established but treatment is based on diagnosis there is serious issue for the treatment-seeking patient.

2.2.4.1 The origins of psychiatric diagnostic categories

Approaches to diagnosis have changed over the years, which has impacted on the way that we ‘treat’. The ‘freedom’ of the original Kraepelinian paradigm, led to challenges around the issue of diagnostic validity and a backlash against psychiatry in general (1960s/early 1970s) which ushered in the neo-Kraepelinian paradigm with its drive to ground diagnoses in biological notions of illness and health (Morgan, 2015) and a hoped-for validity arising from cognitive neuroscience (in terms of providing insights into brain circuitry as a basis for understanding and treating mental illness). This paradigm formed the basis of the DSM-III, a manualised guide to diagnosis, providing diagnosis through checklists of symptoms.

What arose instead from progression in the field of cognitive neuroscience was an awareness of genetic complexity and the importance of social and environmental factors. Alleged ‘biological reductionism’ at the core of the DSM gained further attention on the publication of DSM-V: “All diagnostic categories reduce the complexities of human experience to a set of objective scales that miss the importance

of particular narratives and contexts...” (p153, Morgan, 2015; Timimi, 2013). The issue of taking into account context (personal, social, environmental) comes to prominence; a biomedical approach that ignores these contexts loses relevance with this more holistic understanding of human behaviour in both health and illness.

Without the clarity of biomarkers for mental illness, with co-morbidity being the rule rather than the exception, and access to treatment frequently based on diagnosis, there are significant grounds on which to question diagnosis and the ‘diagnosis-based treatment’ approach.

2.2.4.2 Potential new directions to directing treatment

The biopsychosocial approach, although not without its critics and criticisms (see Babalola et al, 2017), takes into account the personal, social and cultural contexts of the individuals, enabling information to be gleaned from the personal narratives and lived-experiences of individuals living with, or with a history of, mental distress (Grant et al., 2015; Morgan, 2015; Melchert, 2010; Bablola et al., 2017; Davis, 2010). With this, and an awareness that diagnosis-based treatments are in question, comes a growing interest in trans-diagnostic approaches to treatment. Trans-diagnostic approaches, rather than relying on diagnosis, examine underlying common psychological processes and target these in treatment; there appears to be promise in this approach (i.e. Newby et al., 2015; Chalder & Willis, 2017). Binnie (2013) stresses the importance, with a transdiagnostic approach, of a thorough problem-based individualised formulation, although a need for greater clarity in terms of case conceptualisations has been raised (NewHarbinger, 2014). Such clarity can be seen in the transdiagnostic meta-model of MUS/PPS (medically unexplained symptoms/persistent physical symptoms) created by Chalder & Willis (2017) whereby they map processes (behavioural, cognitive, emotional and social) to the goals of interventions then to the specific strategies/techniques to be used.

2.2.4.3 Updating healthcare: involving the patient

With improved understandings regarding how individuals interact with healthcare, the links between mental and physical health, how to better enable compliance with treatment programs and medication, healthcare provision is, understandably, moving in the direction of co-production (Crimlisk, 2017; Chambers et al., 2017; Batalden et al., 2016); understandings and approaches, such as the biopsychosocial and

transdiagnostic, are more amenable to co-production. They represent a move away from the diagnosis-treatment-discharge model; in a socio-political environment where healthcare funding is under increasing pressure and doubt, evolving healthcare in this direction may be challenging.

2.2.5 The challenges of defining and identifying disordered eating

The strict definitions for EDs (including some reference to weight-ranges) provide a clear cut-off point for what is considered to be 'clinically significant' and requiring treatment. However, with DE noted as common among individuals classified as 'overweight' and 'obese' (adults and children), and with the lack of enquiry regarding eating practices of those who maintain in the 'healthy' weight range, there is potentially a much greater need for treatment than diagnosis and weight presentation alone would suggest. If we also consider the secrecy around certain DE practices and the implicit condoning of extreme dieting practices, as well as the health implications for individuals engaging in DE, the size of the problem is potentially much larger than statistics on ED would suggest. If treatment is not received and the health issues remain, this ultimately has the potential to impact not only on the individual in terms of health and quality of life, but also on future healthcare costs: these hard, financial aspects must also be examined as they form an important and practical part of rationales for healthcare.

2.3 The Costs:

2.3.1 Costs of Eating Disorders

The Beat report into the costs of EDs (2015) estimate costs to the NHS annually in the region of £3.9 - £4.6bn. However, they also add two further cost estimates: costs to sufferers and carers, between £2.6 and £3.1bn annually; and economic costs (lost income etc.) in the region of £6.8 - £8bn annually.

Together, these cost estimates total between £13.3bn and £15.7bn per year.

2.3.2 Costs of obesity

For the issue of overweight and obesity the picture is more complex with costs being harder to 'bracket': being overweight or obese increases the likelihood of certain other health conditions (i.e. cardiovascular disease, type 2 diabetes, some cancers, high blood pressure, fatty liver disease, osteoarthritis, sleep apnoea etc.) although people who are

not overweight or obese can also present with the same health conditions - isolating what is and what is not directly attributable to weight is a challenge. However, McKinsey (2014) report that costs to the NHS of overweight and obesity were between £6 and £8bn annually (potentially rising to between £10bn and £12bn in 2030). They also estimate costs to employers in the region of £7bn annually, with the wider economic burden to society being higher still. The report does not provide an estimate for the personal costs to individuals and carers.

Together, these (incomplete) cost estimates total around £13bn annually. Attempting to gain a more complete picture we could take into account McKinsey's figure of £10bn (the annual spend on type II diabetes) although considering the range of health conditions with a higher likelihood for individuals who are overweight or obese, this would still be an incomplete estimate.

Williams et al. (2018) provide an estimate of overall costs of obesity in the UK to be closer to £27bn a year (citing Treasury estimates of £46bn).

2.4 The Models:

Evidence-based treatments are underpinned by models of the health condition they are treating - they form the basis of treatment, creating a framework and direction. Clinical practice can sometimes appear 'disconnected' from the underlying models so it is helpful to return to the models and evidence to establish the 'start point' for treatment(s).

2.4.1 Models of EDs

The **socio-cultural** model posits that the unfavourable comparison of body-image with the prevailing 'thin-ideal' leads to dissatisfaction and DE practices in order to 'correct' the body (Stice, 1994, Stice & Shaw, 2002, Stice, Shaw & Nemeroff, 1998). This situates the crux of the issue at the interface between individual and society, suggesting a key role for media portrayal of the 'right' body types, also emphasising the perceived pressure to achieve this body type(s). Vander Wal et al. (2008) suggest that there are factors within the individual that may be key though, namely 'social sensitivity' ("...heightened awareness of and reactivity to social interactions." p.282) which underlie a dependence on "external standards of performance and appearance" (p.282) that may be considered 'excessive'. There is evidence to suggest that appearance-based peer comparisons fuel body dissatisfaction (Stormer & Thompson, 1996; Vander Wal & Thelen, 2000, Jones, 2001). However, it is the perception of being overweight rather than the reality of body

size that is key in terms of the negative impacts of the internalisation of the 'ideal' body-image.

Paquette & Raine (2004) point out that the contradictory nature of messages within our current sociocultural context, on the one hand emphasising the 'thin-ideal' and on the other encouraging over-consumption, creates a toxic environment. In a non-eating disordered participant group, they found that individuals were susceptible to the interpretation of the meaning of comments (hence influenced by the nature of their relationship with the person commenting). Comments within a health context were *not* re-interpreted but taken at face value, in part due to the setting but also due to the perceived authority of the message-giver (e.g. doctor). The importance then of comments and messages within a health setting becomes of paramount importance in terms of body-image (see also Zola, 1973).

However, the role of body-image among ED patients may come after the onset of DE rather than act as a driver. This model also does not speak to the concept of 'control' which appears as a recurrent theme amongst individuals battling EDs.

The **cognitive-interpersonal** model (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) suggests that elements from the cognitive, socio-emotional and interpersonal act together to cause and maintain AN. Although based around AN, there are elements that broaden its applicability to a wider range of EDs. The model suggests that the initial restriction produces a feeling of wellbeing. Subsequently, in the starved state, eating becomes challenging as it results in unpleasant physical sensations. The preoccupation with food provides a form of 'numbing' regarding any other emotions, which they suggest is valued by individuals with AN. The reactions and responses from others play a role, initially in reinforcing the weight-loss, and then through concern and attention, the latter responses being provided without the need for direct communication from the individual, reinforcing the pro-anorectic beliefs. Certain predisposing traits are posited - obsessive-compulsive traits, set-shifting issues (cognitive inflexibility) and weak central coherence (a tendency to focus on the detail with an inability to see the 'bigger picture'). Additionally, certain social and emotional traits impact on the ability to relate interpersonally (avoidance of emotions, difficulty interpreting social signals, difficulty signalling emotions, negative focus, and issues understanding self and others). The MANTRA treatment approach (Schmidt et al., 2014) was developed from this model and targets particular aspects of cognition whilst also supporting families and carers to adapt their social communication style.

The **self-schema** model (Stein, 1996) suggests that there is an identity disturbance and lack of self-definition among patients with an ED diagnosis. Schemas, knowledge structures, constructed through interaction, serve as foundations for understanding and responses to subsequent interactions. They hold both declarative (statements, understandings) and procedural (patterns of behavioural response) knowledge and, as such, guide both the thoughts, feelings and beliefs that one has about the self as well as the behavioural responses to events. Self-schemas vary in terms of the number within the self-concept, the content, associated evaluative attitudes and accessibility. Markus et al. (1990) suggest that a greater number of positive self-schemas in childhood facilitate a positive transition to adulthood, and vice versa. Support for this proposal comes from Stein and Nyquist (2001) who suggest that Cognitive Behavioural Therapy (CBT) approaches focusing on weight and food may actually serve to exacerbate the negative schemas; they offer an alternative of promoting the development of new positive self-schemas as a central part of ED treatment. This model can also be applied to those with more positive self-schemas from childhood, suggesting that difficult or traumatic life events can serve to disrupt and disorganise these schemas, negatively impacting on the transition to adulthood. Certainly, Bruch (1979) describes AN as "...a struggle for a self-respecting identity." (p255), and the point at which a large number of individuals succumb to an ED does align, developmentally, to the period where a sense of identity and confusion around roles arise (Erikson, 1960; 1963); the applicability of such developmental models to therapeutic framing and approach is not uncommon (i.e. Marcia & Jusselson, 2013; Knight, 2016). This model also provides a framework for understanding the impact of the family in terms of the development of schemas (Stein, 1996) and the 'working self-concept' (Markus & Kunda, 1986) which refers to varying accessibility of different self-cognitions and how some may become 'chronically activated', linking well with the 'compulsive' aspects of ED/DE. Although much of the work around self-schema and EDs/DE focuses on the bodyweight schemas, which may not be relevant to all individuals with DE, there is much within this model to explain the way ideas and behaviours become 'set'. How this might apply to those whose ED/DE onset came later in life (i.e. not at the point of transition to adulthood) is not clear. As there are questions arising from each of these models due to their inability to 'fit' all instances of EDs, the efficacy of treatments based on these models may be variable and we would expect this to be reflected in the treatment outcome data. Common to all the models is an assumption of complex aetiology.

2.4.2 Models of obesity

There is much public discussion of the 'obese population' and some commonly held ideas about the 'solutions'. As can be seen in the approaches to treating obesity, an underlying assumption of a common cause is apparent (diet and exercise/lifestyle) yet there is a vast amount of aetiological variety amongst individuals living with obesity. For example, there are strong connections between certain medications and weight gain (e.g. steroids, birth-control pills, anti-psychotics, epilepsy medication); individuals battling BED are more likely to be overweight or obese; there are connections between SES and weight (PHE, 2014). Understanding the causes for the individual may better enable us to provide appropriate treatment: terms such as the 'obese population' are unhelpful as they mask the complexity. However, a variety of models are proposed:

The **social-ecological** model, taking an ecological systems theory approach, includes individual factors and the larger social, cultural, and environmental contexts (i.e. Ohri-Vachaspati et al., 2014, appendix 8.2). Perhaps the most important study on causes of obesity in the UK is the Foresight report (Butland et al., 2007). Within this large-scale analysis, around 108 distinct contributory factors are listed, illustrated within a 'systems map' analysis (appendix 8.1). Split into sections (Individual Psychology, Individual activity, Activity environment, Food consumption, Biology, Food production and Societal influence) it is notable that the majority of these factors are beyond the control of the individual. Aetiological complexity is very clear from this report.

The **neuropsychological** view (Jauch-Chara & Oltmanns, 2014) suggests that obesity pathogenesis derives from an increase in consumption of palatable high calorie foods in response to stress that sets up a vicious circle "...built on cross-links between chronically enhanced stress axis activity and reward-related mechanisms within the mesolimbic system." (p.95). This model suggests that there is a major role played by the neuronal pathways associated with reward, motivation, learning, memory and cortical inhibitory control and that this needs to be taken into account when developing interventions with a promise of long-term weight-loss maintenance. The role of stress is also cited as a risk factor for obesity by Sinha and Jastreboff (2013), who point to the link between stress and addiction (and addiction relapse) and the reward systems involved with the neurobiological mechanisms underpinning addiction. The DSM-V, whilst not including 'food addiction', did acknowledge a resemblance with other substance use disorders in that it may involve the same neural pathways (p329).

Continuing the focus on physical aspects, the role of **chronobiology**, in terms of circadian disruption caused by the more 24/7 nature of modern living, has been cited as a potential contributory factor and direction for further research (Garaulet et al, 2010); there are suggestions that **maternal physiology** impacts directly on the embryo increasing risks of developing obesity (Jungheim et al., 2010); and further suggestions around the potential role of the **gut microbiome** (Ley et al., 2005).

Bringing together physical, social and psychological factors, the **homeostatic theory** of obesity suggests that a 'circle of discontent' lies at the core of obesity (Marks, 2015), connecting weight gain, body dissatisfaction, negative affect and over-consumption. Homeostasis allows the individual to respond to a changing environment in order to maintain a balance which is essential for health. This model suggests that to be in good health we require four kinds of homeostasis: biochemical, physiological, psychological and social. Acknowledging the biopsychosocial factors, this model suggests approaches to addressing obesity which include reducing the negative judgements on body-image and moving diets in a healthier direction in general. Replacing the emphasis on weight reduction with a promotion of optimal health is viewed by some researchers as a more productive route in terms of improving health outcomes (Cadenhead et al., 2012; Logel, et al., 2015).

What we understand scientifically however does not necessarily translate to or inform actions. Bombak (2014) points out that, in the face of improved and improving understandings of obesity aetiology within the scientific community, the public health messages are remaining the same, namely that individuals living with obesity must take responsibility for 'correcting' their 'wrong' bodies.

2.4.3 Acknowledging complexity in practice

The models for both EDs and obesity underline the aetiological complexity, which strongly suggests the need for treatments which acknowledge and address this complexity but is this reflected in practice? Many countries have a body, such as NICE in England, who attempt to bridge research and practice. These bodies provide guidelines, routinely updated in-line with current evidence, for pathways and treatments.

There are practical barriers to enacting change in practice (i.e. resource in terms of premises, policy, training, pathway creation, staffing) and sometimes there appears to be a 'disconnect' between research, practice and patient need, however, as NICE provide the

framework for treatments in the UK, their guidelines will provide an overall picture of what treatments are on offer currently.

2.5 The Treatments:

2.5.1 NICE Guidelines

2.5.1.1 ED: Guidelines (NG69, 2017)

The general principles of care emphasise sensitivity to the stigma and shame around these issues and the need to tailor interventions to the individual. They stress the importance of including family and carers (who should have equal access to treatments) and equal access to treatments regardless of gender, SES, etc..

They also stress the need for:

- awareness of the possibility of bullying, teasing, neglect and abuse (especially with children and young people);
- good communication;
- co-ordination of care;
- impact of the individuals' various environments should be assessed and addressed;
- adequate training for HCPs.

2.5.1.2 Obesity guidelines (CG189, 2014)

General principles of care are split into different sections for adults and children. For adults, they commence with the importance of:

- having the correct equipment;
- for HCPs to discuss the interventions available and tailor these to the person's preferences;
- long-term, non-discriminatory follow-up by a trained HCP.

2.5.1.3 Comparing General Principles of Care for EDs and Obesity

The general principles of care for obesity do not reflect the current understanding of the complexity of the issue, implying an emphasis on physical health, insight and awareness on the part of the individual, and a focus on the individual alone. The broader biopsychosocial understanding of EDs is apparent but lacking in CG189.

2.5.2 NICE recommended treatments

2.5.2.1 ED recommended treatments

Recommended treatments include a range of diagnosis-specific psychological therapies and monitoring/treatment of physical issues. Co-morbid mental health issues may be treated simultaneously if appropriate.

Provision for EDs is not consistent across the country (i.e. McCubbin, 2016; Beat, 2015), however, the guidelines provide a clear steer for HCPs, stressing the importance of considering the bigger picture for the individual.

2.5.2.2 Obesity: Recommended treatments

The treatments on offer are:

- lifestyle interventions;
- behavioural interventions (which include psychological input);
- physical activity;
- dietary change;
- pharmacology; and
- surgery.

There is a tiered structure:

Tier 1 - General advice on healthy weight and lifestyle (primary care);

Tier 2- Diet and physical activity (commercial weight management providers such as WeightWatchers/Slimming World and exercise on time-restricted prescription, commissioned by local authorities);

Tier 3 - Diet and physical activity; consider drugs (clinically-led multi-disciplinary teams, no set format, commissioned by Clinical Commissioning Groups (CCGs). Some psychological input in some areas of the country);

Tier 4 - Diet and physical activity; consider surgery (bariatric pathway, until very recently commissioned by NHS England (no set format)).

Provision at all tiers is not consistent across the country with some areas lacking provision at any tier (Capehorn et al., 2016; PHE, 2015).

2.5.2.3 Comparing recommended treatments for EDs and Obesity

The focus for obesity treatments is physical and based around weight loss and there are no nutritional guidelines present. Psychological issues are not dominant within

obesity guidelines. There is no requirement to consider the bigger picture, wherein lies the complexity regarding overweight/obesity.

2.5.3 NICE treatment goals

2.5.3.1 ED treatment goals

Interventions are tailored, so goals vary. Overall goals are to eliminate the DE behaviours and restore a healthy balance and lifestyle. With individuals presenting at a very low body weight this includes weight restoration to within the 'healthy weight range' (BMI 18.5 and above).

The overall approach encompasses elements from the biological, psychological and social domains.

It is noted that some people will experience relapse and many services are set up to allow for rapid re-access in these instances.

2.5.3.2 Obesity treatment goals

The general goals of the treatment are weight-reduction and increased physical activity. The outcomes are measured using standard physical means (weight, HbA1c (for diabetes), blood pressure and so on) with the main emphasis on weight-loss, making the guidelines very focussed on biological factors. Weight-loss maintenance and the nutritional balance of the diet are not monitored.

The guidelines recommend long-term follow up although the period is not specified. The possibility of psychosocial stress or other psychological issues are mentioned as issues for potential enquiry, but there are no specific goals around such aspects within the guidelines.

2.5.3.3 Comparing treatment goals for EDs and Obesity

Within ED treatments there are broad-ranging goals which encompass the bigger picture for the individual. Within obesity treatments the goals are focussed on weight and biological factors. There are no goals around nutrition or psychological health.

2.5.4 Treatment efficacy

2.5.4.1 ED treatment efficacy

Recovery rates reported by Beat (2018) indicate that around 45% of individuals with AN or BN report full recovery, approximately 30% are improved and 20% suffer chronically. Recovery rates for BED are not readily available. Services for individuals with a BED diagnosis are not always present within ED services (personal communication).

2.5.4.2 Obesity treatment efficacy

Rates of obesity continue to rise (NHS digital, 2017). Treatment efficacy may best be assessed at specific tier level.

Tier 1: Evidence of the efficacy of providing guidance on healthy diet and exercise is poor: the information is heard, but the behaviour is not changed (i.e. Gordon et al., 2012; Croker et al., 2012; Marteau, 2018).

Tier 2: The long-term efficacy of commercial weight management programmes in terms of sustained weight-loss is at best unclear and at worst poor (i.e. Jebb et al., 2011; Jolly et al., 2011; Ahern et al., 2011; Vakil et al., 2016), studies regarding cost-effectiveness of commercial weight-loss programmes also vary (i.e. Cobiac et al., 2010; Jolly et al., 2011) and there is no obligation for commercial weight management providers to store and provide long-term outcomes (Heyes, 2006).

Tier 3: These services vary across the country in terms of structure and approach (PHE, 2015), making efficacy difficult to assess. The patient population for these services are complex (Butland et al., 2007) and may contain a significant number of individuals with BED (Gluck et al., 2004), anxiety disorders (Garipey et al., 2010); maltreatment in childhood (Mason et al., 2016); Post Traumatic Stress Disorder (PTSD, Farr et al., 2014); chronic pain (Paley & Johnson, 2016); and mental illness is often comorbid (Avila et al., 2015). This makes it difficult to establish what the structure at tier 3 should be.

Tier 4: Typically, patients will achieve maximum weight-loss at 1-year post-surgery (Voils et al., 2017). Many patients maintain 'significant' weight-loss but weight regain is not uncommon (around 10-20% of patients regaining 'significantly' or 'excessively', Cooper et al., 2015; Courcoulas et al., 2013; Sjostrom, 2013). There is a lack of outcome data for bariatric surgery; many studies end their 'long-term outcomes' at 3 years. Current data outcomes are mixed, suggesting both promise (Sheng et al., 2017,

Booth et al, 2014, Haruta et al., 2017, Colquitt et al., 2014; Herpertz et al., 2003; Bocchieri et al., 2002) as well as concern (Pinto et al., 2017; Pizato et al., 2017; Cooley, 2017; Golomb et al., 2015; Crawford et al., 2017; Herpertz et al., 2015), physically and psychologically, making long-term cost-effectiveness difficult to determine (Wang & Furnback, 2013). Suboptimal outcomes increase post-operative costs (Shah et al., 2016).

The importance of psychological input at tier 4 is clear (Sogg et al., 2016; Boeka et al., 2010; Sogg et al., 2015; Jumbe et al., 2017), but not all tier 4 services include this as part of a standard package of care.

2.5.4.3 Comparing treatment efficacy for EDs and Obesity

Recovery regarding eating/weight-related conditions is clearly challenging. The more comprehensive approach for EDs is promising although relapse is accepted as common. With challenges regarding determining treatment efficacy for overweight/obesity and obesity rates continuing to rise, there are clearly questions around how we are approaching treatment for weight-related issues.

Contrasting the promise regarding treatment from the ED approach with the apparent inadequacy of the obesity approach, and considering the complexity around weight-based judgements and the many roles of food alongside challenges of identifying DE, now would appear to be an appropriate time to take another look at the issues around weight, body-image and eating behaviours.

2.5.5 Weight-based judgements?

Examining the treatments, there are several issues here:

- Although these are health issues with significant costs to the economy, individuals, community and healthcare, resource allocation does not appear to reflect this, with evidence that provision across the country amounts to a 'postcode lottery' (PHE, 2015; Royal College of Physicians (RCP), 2013; Exasol, 2011, 2015; McKinsey Global, 2014; PHE, 2015; National Obesity Forum, 2014; Beat 2015).
- ED outcomes vary although the guidance acknowledges the complexity. Beat's (2018) statistics suggest a complex picture where 10% of those with an ED meet AN diagnostic criterion, around 40% are diagnosed as BN and the rest fall across the other diagnoses. Within the AN category there are individuals who maintain a

low weight but do not fit the 'skeletal' images that are typically associated with AN and there are various 'myths' around EDs that form the basis of assumption, both in the general population and the healthcare community, with many individuals with AN facing repeat trips to services while their weight is reducing prior to getting the help they need, sending a message that to be 'ill enough' you have to be very underweight.

What happens then, when you have an ED but your weight presentation is not 'underweight'?

- Obesity outcomes are poor and the guidance does not acknowledge the complexity, placing a focus on the physical aspects. These guidelines are based on weight presentations, guided by the severity of the obesity. The common core across the tiers is to advise to change diet and lifestyle: there is an implicit assumption that the individual has insight into the cause of their higher weight, can discuss what to do about it, and change it. This ignores the complexity of our relationship with food, the meaning it holds for us, the purposes it serves, the impact of the environments in which we live and work; the potential complexity of the causes of the higher weight are not acknowledged and neither is the psychological work that has to be done to change behaviour. With diets condoned, accepted and promoted in society, the message here appears to be 'control yourself'.

Is our current approach to obesity unduly influenced by deep-rooted assumptions on appearance and weight?

Our current healthcare system is under greater pressure than ever before which will, at least in part, explain issues with provision, but these are complex issues: there may be other factors 'standing in the way'. There are deep-rooted assumptions regarding appearance and weight which underpin and explain 'accepted' discrimination on the basis of body size (Beat, 2013); 'body-shaming' is prevalent. There is also a stigma around issues with mental health that, although more publicly challenged (i.e. Time to Change), prevails. From a biopsychosocial perspective, stigma and its impacts on the individual would have the potential to affect ability to engage in health-improving behaviours and/or treatment, as such an examination of impact of stigma will be helpful when considering how best to support individuals with improving their health.

2.6 Stigma (societal)

Stigma, a 'mark of disgrace', does not occur in isolation but is set against a 'backdrop' of norms, values and expectations (Becker & Arnold, 1986); there is evidence to show that it plays a role in adding to the challenges for individuals with EDs as well as individuals living with obesity.

2.6.1 EDs

The stigma of mental health issues impacts on the individual, their family (sometimes across generations), the institutions who treat them, staff and even the associated medications (Sartorius, 2007). It can impact on health-seeking behaviours; physical illness in individuals with mental health issues are sometimes perceived and treated differently with referrals to specialist treatment being less likely (Bharadwaj et al., 2017; Corrigan et al., 2015). Where individuals have complex needs this can mean the burden of stigma is even worse (The Lancet editorial, 2016).

There is evidence of additional stigma attached to EDs, with more assumptions around personal responsibility, 'attention seeking', and negative personality traits (Roehrig & McLean, 2009; Puhl & Suh, 2015). That the associated stigma acts as a barrier to both disclosure and seeking treatment has been shown (i.e. Doley et al., 2017) but the nature of the treatment approaches (and the HCPs themselves) is also important. Bannatyne & Stapleton (2016) found that patients perceived treatment as punitive, blaming and placed too much emphasis on the physical aspects of the ED. Blaming self incites shame which, in turn, can exacerbate the ED behaviours; the more the behaviours become engrained the worse the condition becomes.

Stigma for individuals with EDs is a very big part of the problem.

2.6.2 Obesity

Larger bodies in society are viewed through a frame of blame, a 'discourse of culpability' (McQueen, 2001). Gard (2009) states that "...the obese body has emerged discursively as a self-evident marker of individual moral failing, rampant desire and a society in decline." With fat-shaming acknowledged as prevalent and problematic, the issue is recognised internationally (www.stigmaconference.com). Levels of weight stigma in the states are judged as comparable to rates of racial discrimination (Puhl & Heuer, 2009) with individuals being classed as "...lazy, unmotivated, lacking in self-discipline, less competent, non-compliant and sloppy." (p941). They cite disadvantages in employment;

healthcare; education; the media, with many adverts presenting a message that “...weight is easily modifiable and that successful weight-loss is a simple matter of personal effort.” (p951) with news media framing obesity as personal responsibility. The negative impacts include depression, self-esteem, body-image dissatisfaction, coping strategies and psychological wellbeing, including worse eating behaviours, physical activity and poorer cardiovascular outcomes (Puhl & Heuer, 2009). The links between weight stigma and poorer health outcomes, psychologically and physically are well established (Hunger et al., 2015; Spahlholz et al., 2016; Lydecker et al., 2016; Vartanian & Porter, 2016; Nolan & Eslleman, 2016; Tomiyama, 2014; Major et al., 2012; Major et al., 2014).

Internalised stigma exacerbates this further (Farhangi et al., 2016) with ‘just world beliefs’ reinforcing perceptions of failure and acceptance of personal responsibility (Carels et al., 2009) and Douglas & Varnado-Sullivan (2016) evidenced a link between weight bias internalisation and increased DE. In short, weight stigma amplifies the negative impacts of obesity as well as presenting as an additional barrier to making positive health behaviour changes.

Does this stigma project into healthcare provision?

2.7 Stigma (healthcare)

With the dominance of a biomedical approach comes assumptions regarding objectivity on the part of the practitioner: that the illness/disease is ‘separate’ from the person, that the illness follows a ‘cause and effect’ logic, and that the doctor will remain ‘distant’, taking an objectivist philosophy (Wilson, 2000). Expectations of objectivity, that a practitioner will not be swayed by ‘common’ stigma and assumption, lies implicit in the exchange between patient and practitioner. HCPs though are not immune to the influence of societal values, norms and assumptions.

2.7.1 Assumptions regarding EDs

There exists a dominance regarding the ‘anorexic image’ for EDs that extends into healthcare. McCubbin’s (2016) enquiry into mental health trusts in the UK indicated that a third of NHS trusts still used weight to determine whether patients qualified for treatment: all responding trusts stated they used it as part of their criteria for diagnosis and treatment; some used it as a primary measure with patients being denied treatment if they were not below a specific BMI (i.e. only ‘underweight’ individuals with an ED being taken seriously). Even as recently as 2017 (Reas et al.), there is evidence of on-going

assumptions from HCPs that individuals with EDs would be female and thin, along with a perception of 'choice' as to whether they continue with their behaviours (an assumption not made for individuals with other mental health conditions such as schizophrenia); and there are assumptions that EDs are 'trivial' and 'self-inflicted' (Griffiths et al., 2014). Perceptions of treatment as 'punitive' and 'blaming' are recorded (Bannatyne & Stapleton, 2016); McNicholas et al. (2016) suggested that ED symptoms were less well recognised than other mental health issues and that HCPs preferred to work with conditions other than EDs.

2.7.2 Assumptions regarding obesity

Phelan et al. (2015) reviewed literature regarding obesity finding that HCPs frequently view obesity as an 'avoidable risk factor', holding strong negative attitudes and stereotypes which influenced perceptions, judgements, interpersonal behaviour and decision-making. The issue of 'controllability' has also been found by other researchers with evidence of bias coming from a variety of HCPs across a range of healthcare settings (i.e. Garcia et al., 2015; Lindhardt et al., 2013; Mulherin et al., 2013; Pont et al., 2017). Where there is overlap between EDs and obesity (i.e. BN and BED) there also appears to be a lack of understanding from HCPs (Puhl & Heuer, 2009; Reas, 2017). BED tends to be connected to personal responsibility more than AN and BN and is also seen as the least debilitating/serious of the EDs (Puhl & Suh, 2009; Reas, 2017). (See also section 2.1)

2.7.3 Common assumptions regarding eating and weight-related health conditions

There is evidence of assumption and stigma, in both society and healthcare, creating additional difficulties for patients requiring treatment for DE/ED that are unnecessary and may revolve around the appearance of the individual, particularly in terms of their weight presentation. Health conditions that involve weight are more likely to be assumed to be under the control of the individual, the individual more likely to be judged as 'personally responsible' for their condition.

2.8 Is weight getting in the way?

2.8.1 The impact of assumptions based on weight

Our body size is the basis of assumption: in society, regarding status, identity, worth, morality, work ethic, intelligence; in healthcare, in terms of potential diagnoses, advice,

treatment, potential compliance. Assumptions around different weight-presentations are fundamentally different. These assumptions are rooted in history and the idea that outward appearance and 'beauty' are indicative of the psyche and underlying character. A pervasive desire for simplicity, where complexity exists, appears to remain regarding the relationship between weight and health, with food-use and weight presentations linked to morality, worth and health. With 'healthy' weight presentations there is an assumption of health yet we know that the majority of individuals with EDs do not meet criteria for AN (Beat, 2018) nor present with the 'anorexic-image' which dominates the media; disordered eating takes many forms and weight presentations – we have to broaden our view of DE.

Taking into consideration the media focus on an 'obesity epidemic' and current acceptance of 'crash' and 'fad' diets, which frequently involve extreme caloric restriction or restriction/elimination of particular food groups, and the dieting approach in general (with various commercial concerns running group programmes for weight-loss, including some that are available on prescription through the NHS) we can question whether nutrition and health-promoting/health-maintaining behaviours receive adequate emphasis.

Are we inadvertently encouraging DE across the weight spectrum?

We have no data regarding the prevalence of DE in the general population however there is evidence suggesting that DE is prevalent amongst children and adults living with overweight/obesity (i.e. Do et al., 2018; Nystrom et al., 2017). An assumption that DE is indicated by lower weight presentations is clearly problematic.

The evidence is clear, we cannot make assumptions about disordered eating based on weight, yet our approaches to weight-related health conditions appear to target weight rather than viewing it as a symptom.

2.8.2 Exploring individuals' experiences

Much of the research regarding EDs has focussed on AN and BN and we may question this focus considering diagnostic prevalence statistics from Beat (2018) and others (i.e. Dovey, 2010). Beat's research on patient experience suggested that HCPs had some way to go in terms of providing timely and effective responses to EDs and we know that many NHS trusts still use weight as a significant part of their process in determining access to treatment pathways. With weight (BMI specifically) serving as a key access criterion for services for weight management for individuals presenting at higher weights, an

individual's weight presentation is playing a significant role in terms of gaining acknowledgement and, crucially, being given access to treatment. Is this an effective means of directing individuals through the healthcare system?

Although we have a significant amount of research examining aetiology, models and treatment efficacy for EDs and obesity and an awareness that we have some way to go in terms of providing effective treatments, we are lacking research regarding individual experience as 'consumers' of our healthcare approach. We know that eating behaviours and weight bring judgements – how significant are those judgements and perceptions to the individual seeking help? Are our collective assumptions around weight preventing access to treatment for DE?

2.9 Research aims

Research has typically examined EDs and issues of overweight/obesity separately, emphasising the assumptions, predicated on weight presentation, regarding health, potential diagnosis and potential treatments. Yet consideration of patient perspective forms an essential part of research and healthcare. Consequently, this research seeks to explore the experiences of individuals with DE, across the weight spectrum, to gain insight into the impact of societal assumption and stigma around weight; by taking the novel approach of 'removing' the filter of weight, this research seeks to explore patient perspective; a crucial part of the bigger picture around understanding and effective treatment development and provision.

This research aims to conduct a scoping exercise, exploring the experiences of individuals across the weight spectrum who have lived with/experienced DE, within a variety of contexts (family, social, healthcare), to determine their perceptions of how weight has influenced their treatment in these contexts, and to gain insight into how weight may be influencing views and responses to DE.

The aims of this research are:

1. To explore experiences of disordered eating across the weight spectrum within society and healthcare.
2. To examine experiences of the approaches of HCPs with patients at different weight presentations.
3. To explore ways of improving the approaches to ED and DE in order to maximise long term health benefits.

3 Methodology

The 'a-contextualising' of health is one of the key criticisms from critical health psychology (Hepworth 2006); bringing the context into our understanding (Murray, 2004) was something that I felt was key. 'Context' had presented as an important factor within my own experience of working with patients with an ED diagnosis as well as individuals living with obesity and there is evidence to suggest that individuals at different weight presentations may be having different experiences across a variety of contexts, including different responses in a healthcare setting, which may be impacting on their ability to recover from the difficulties of DE (see sections 2.7 and 2.8). There is the potential, through taking a critical health psychology position, to appear 'non-constructive' (MacLachlan, 2006) and, with this in mind, a pluralistic and open stance was adopted with the goal of working towards better understanding, provision and a decreasing of health inequalities.

To facilitate and embody this stance within a research framework necessitates careful consideration of the approach taken to access and analyse the experiences. A qualitative methodology is well suited to an exploration of lived experiences but with the choice of a qualitative approach comes the need to ensure quality without the standard validity and reliability measures that come with a quantitative methodology.

3.1 Quality assurance process

Fundamental to all qualitative research is the understanding that there is no such thing as 'objective' knowledge as research is understood to be impacted by the knowledge, beliefs and understanding of the researcher (Camic, Rhodes & Yardley, 2003). As such, qualitative research requires an appropriate set of criteria which can be used as a yardstick for quality in a similar way to the use of validity, reliability and generalisability within quantitative research frameworks. Establishing such a set of criteria within qualitative research is, arguably, challenging, as the different methodologies may rest on different epistemological and ontological underpinnings, which have an impact on the way we might observe and measure aspects of quality. Yardley makes a strong argument for the importance of 'quality criteria' to effectively establish the value of qualitative research in health psychology. Indeed, to promote the role of qualitative research in generating and refining treatment guidelines and in improving the approaches of healthcare professionals, establishing and utilising such quality criteria is of crucial

importance. Yardley's (2000) guidance on establishing quality, using four flexible principles (sensitivity to context; commitment and rigour; transparency and coherence; impact and importance), can be applied across all forms of qualitative research. Yardley stresses though the importance of generating "...a wider appreciation of the inherent complexities and ambiguities associated with evaluating qualitative studies." (p224) rather than jumping to "...a simplistic and premature definition of what constitutes good qualitative research..." (p224). Tracy's (2010) "Big-Tent" criteria add detail to and also separate out some of Yardley's principles which results in a more highly detailed framework for assuring quality, making them a good choice of quality framework for the current research.

Tracy's eight criteria (worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethical, and meaningful coherence) can be seen to apply differentially at different stages of the research. An explanation of each criteria, at which phase they applied and how the criteria have been met are contained in the appendix (8.3).

3.2 Research framework

3.2.1 Ontological assumptions

With DE there are clear risks associated with the extremes of weight as well as the practices (i.e. binge/purge). In addition, there are influences from the cultural stance on body-image and the role of food and fashion manufacturers. However, the individual perception and response to these realities is subjective and open to interpretation; how much one is impacted by these social/cultural aspects is varied and forms part of some of the models of ED and obesity. As such I felt that critical realism was a 'best fit' for this subject. It is also the approach that I align myself with philosophically as a researcher and my own journey of personal and professional identity is something I understand within the critical realist framework.

3.2.2 Epistemological assumptions

Contextualism is concerned with understanding how individuals make meaning of their experiences within contexts. Without an assumption of a single reality, it allows us to accept that people make meaning of their experience as well as noting that social context impinges on these meanings. With the socio-cultural model of DE and the social-ecological model of obesity particularly, the contextualist epistemology is a good fit. It

also resonates well with the importance this research places on the contextualising of health.

3.2.3 Methodology

3.2.3.1 Patient and public involvement (PPI)

The importance and value of PPI to healthcare research has been well documented (Brett et al., 2014) with benefits reported at all stages of research from user-focused objectives, through the development of user-friendly information, to consumer-focused interpretation of data and beyond. Beat, the UK's ED charity, have experience of supporting individuals with DE/ED, their families and friends, healthcare professionals and researchers. Their knowledge in this area, as well as their support for researchers, positions them as ideal PPI partners. Following the securing of provisional agreement from Beat to support my research (pending ethical approval), I discussed the research's purpose and methodology with their research officer. Their suggestions, along with discussion with my supervisors and within my progression viva, helped refine the overall methodology, online questionnaire and interview schedule, with further support from Beat provided in terms of recruitment (appendix 8.4 - 8.9). Piloting the questionnaire with colleagues and some individuals with experience of EDs, DE and weight issues, provided feedback on the length and feel of the online questionnaire which, with guidance from Qualtrics, refined the 'look' further, making it less 'text-heavy' (in an attempt to reduce the possibility of overwhelming potential participants).

3.2.3.2 Questionnaire

An online questionnaire (Qualtrics, appendix 8.8) was used to recruit participants and collect demographic data, including BMI, in order to allow for sampling across the weight spectrum. Data regarding diagnostic status and treatment experiences were also gathered.

The questionnaire was kept minimal, following feedback from the pilot, supervision and through consultation with Beat (appendix 8.4).

3.2.3.3 Interview

The semi-structured approach (by phone) was taken to prevent too much direction from the researcher, allowing the individual's experience to take dominance (aligning with the ontological grounding). This approach suited the research goals well as it allowed each individual to talk freely about their experiences without being impacted by the presence of others (i.e. within a focus group). The method/mode was practical as it avoided the issues of location and travel, enabling participants to have the interviews at times that were convenient for them, and also ethically appropriate, taking into consideration the sensitive nature of the subject matter (see section 3.3.1) and the vulnerability of individuals who have potentially experienced stigma (see sections 2.7-2.8).

A framework for the interview was developed (appendix 8.9) enabling access to the information required to answer the research question regarding experiences across different contexts, as well as to reflect the epistemological stance. The framework was reviewed and developed in supervision, with Beat and in discussion with individuals with experience of ED/DE. The start point of the interviews remained constant with the framework being used as a reference point by the researcher.

3.3 Ethics and risk

3.3.1 Sensitive research

The participant group, as well as the subject matter, places the current research in the realm of 'sensitive research' which requires a particular focus on ethical considerations (Dickson-Swift et al., 2008). Lee & Renzetti (1993) define research on sensitive topics as follows: "...where research intrudes into the private sphere or delves into some deeply personal experience." There is the potential for "mortification of self" (Goffman, 1973) whereby the researcher, by enquiring into the private world of the participant, that private world may be destroyed. As Cowles (1988) explains, when we enquire "...into the private worlds and experiences of subjects, sometimes evoking strong emotional responses and sometimes pursuing thoughts that might otherwise never be revealed, consideration of the common ethical issues may not be enough." Having control over our lives involves having control over what others know about our lives, including the private and personal; there are potential risks for both participant and researcher alike (Goffman, 1973). However, Lee & Renzetti are clear that sensitive research, with its issues and

problems, must be confronted in a serious and thorough manner, and that we must not shy away from such research on the basis of risk. The potential for positive outcomes is also present (i.e. 'research as intervention', Patton, 1990; and Hutchinson et al. (1994) point to the potential for catharsis, empowerment, healing and being heard, to be at least as present within sensitive research as the potential risks).

The risks were considered carefully in PPI consultation and supervision, changes were made to the questionnaire element and additional safeguards brought in to mediate risk (appendix 8.6). Selecting a one-off interview is helpful regarding the possible risks to both researcher and participant, but also provides additional potential benefits such as enabling individuals to disclose without the complications of an on-going relationship, lowering the possibility of the researcher becoming emotionally involved and issues with 'endings'.

The importance of informed consent is, arguably, more important with sensitive research (Bosk, 2002) and as such, particular attention was given to disclosure regarding the research to participants, ensuring that participants fully understood what they were consenting to and that their participation was voluntary, providing varying means of support and multiple opportunities to withdraw (appendix 8.8 – 8.10). Considering my own positioning with this research (appendix 8.11), as well its sensitive nature, I was conscious of the potential emotional impact on myself (Lofland & Lofland, 1995) and built in additional safeguards around this.

3.3.2 Risk assessment and management

The risk assessment and ethics application were in-line with the British Psychological Society's ethics code and approved by the university ethics board (appendix 8.6).

3.4 Procedure

3.4.1 Recruitment

Recent reports on access to treatment for individuals with EDs and also individuals living with obesity reveal disparity in terms of provision across the country, with some areas being well-provided for and others with very little (McCubbin, 2016; Beat, 2015; Capehorn et al., 2016; PHE, 2015; RCP, 2013). In terms of the areas with provision for treatment, the treatment was also noted to vary. In light of this variation across the country, focussing the research within any single NHS area would provide skewed data.

As such I decided to attempt to collect data across the country through online recruitment. An online questionnaire (appendix 8.8), accessible by computer and phone, was promoted via Twitter (appendix 8.8.5), using Facebook (appendix 8.8.6), from direct contact with peer support groups listed by Beat (appendix 8.8.7) and also by Beat on their website and Facebook page (appendix 8.8.8). The questionnaire was open for a limited amount of time. It was acknowledged that recruiting with support of an ED charity would skew the recruitment towards individuals who have both acknowledged their DE experience as well as sought some support, if only in the form of contact with the charity. This was reviewed in supervision; it was felt that, as individuals with DE frequently talk of a period prior to recognising or acknowledging their own DE, this skew was unavoidable and would present with or without the assistance of Beat.

3.4.2 Sampling strategy

Inclusion criteria were minimal (> or =18 years of age, experience of DE, understanding of the research) and set within the consent form (appendix 8.8.1). In order to capture a good representation across the weight spectrum and across the range of experience of ED/DE there were no exclusion criteria. The participant data from the questionnaire were categorised using the BMI ranges (used within the NHS) to reflect the 'frame' they would be positioned within in terms of healthcare.

In order to sample participants who were representative of each BMI weight category, frequency distributions regarding weights were established (appendix 8.10); a stratified random sampling approach was used to select participants to represent these frequency distributions and the age-ranges within each BMI category. Four participants were selected from within each BMI category.

Participants selected for interview were then contacted (appendix 8.9.1 – 8.9.4), consent was secured and a convenient time for interview was agreed. Interviews were approximately 60 minutes in length and were recorded (with consent from participants) using a digital voice recorder and downloaded onto a password protected computer. Timings for interviews were set around interviewer availability and convenience for the participants. Only three participants contacted at this stage declined, two were due to personal circumstance and one due to anxiety. Two further participants had late changes to their availability – only one was able to re-schedule within the time available.¹

¹ This resulted in one weight category having only 3 instead of the intended 4 interviews.

3.4.2.1 Interview participants

Table 1 provides a summary of the participants interviewed, including the diagnoses they received, whether they had received treatment and their self-perceived recovery status.² Consent was acquired and all interviewees received an introduction and debrief following the interviews (appendix 8.9). For analysis purposes, interviewees were assigned a pseudonym.

Table 1

Interviewee demographics and summary data

<u>Pseudonym</u>	<u>Age</u>	<u>Current BMI category</u>	<u>ED diagnosis</u>	<u>Other diagnoses</u>	<u>ED treatment</u>	<u>Recovery status</u>
'Amber'	19	Under	AN		Yes	In progress
'Ashleigh'	42	Healthy	None		No	Yes
'Emily'	30	Obese	None		No	In progress
'Eve'	24	Obese	BN	Dep, Anx, BPD	No	No
'Grace'	37	Obese	None		No	In progress
'Hayley'	37	Under	AN	Dep, Anx, BPD	Yes	Yes
'Jasmine'	20	Healthy	EDNOS, Atypical BN	Dep, Anx	Yes	Yes
'Joanne'	31	Over	BN, BED	Dep	No	In progress
'Kelly'	26	Over	AN, BN, BED	Dep, Anx	Yes	Yes
'Lucy'	25	Healthy	EDNOS	Dep, DD	No	In progress
'Naomi'	25	Over	None		No	No
'Natalia'	24	Under	AN	Dep, Anx	No	No
'Susan'	25	Obese	BN	Dep, Anx	No	In progress
'Teresa'	21	Healthy	AN	Dep, Anx, OCD	Yes	Yes
'Zoe'	35	Under	None		No	No

² Four participants were selected from each BMI category. The response rate was much higher than expected; in supervision it was agreed to conduct a greater number of interviews to capture a broader range of experiences (16 rather than the intended 12). Unfortunately, there was an insufficient response rate from male participants to justify inclusion in the analysis.

3.5 Analytic approach

3.5.1 Descriptive analysis

Basic descriptive analysis was conducted regarding responses to the initial questionnaire to gain insight into the diagnostic profiles and treatment experience (appendix 8.10, section 4.1).

3.5.2 Qualitative analysis

3.5.2.1 Choice of method

Thematic Analysis (TA, Braun & Clark, 2006) was chosen for analysis of the semi-structured interviews as, in addition to working well with the ontological and epistemological assumptions, it does not place a priori theory on the analysis, facilitating maintenance of a pluralistic approach to theory and allowing the voices of the participants to be acknowledged and heard (a key aim of this research). This is supportive of the explorative nature of the research, and the aim of identifying themes and patterns across the dataset as well as those that may be unique or particular to individuals in any sub-group in the sample. It has been noted that this flexibility enables researchers in the realms of health and wellbeing to explore data at any level, in applied, policy or academic research settings (Braun & Clarke, 2014).

As an explorative piece, it is preferable for the research outcomes to have maximum accessibility, to make them useful across a range of settings (i.e. healthcare, policy, academia, support groups and individuals); TA is ideally suited to maximising accessibility (Braun & Clarke, 2014).

3.5.2.2 Process

Each interview recording was transcribed by the researcher, with participants identified by an identification number only. The transcripts were uploaded into NVivo software where they were analysed using general nodes for context (family, healthcare, social-informal, social-formal and self, with an additional node for improvements). These general nodes were then analysed to identify the sub-themes. A 'weight-blind' approach to the analysis was adopted as a means of taking an open and neutral stance to the identification of themes as well as reflecting the weight-blind nature of DE.

The themes were subsequently examined using the BMI category framework. Shared and distinct themes were noted across the weight categories. Quotes were then chosen to illustrate each theme.

4 Results

The descriptive statistics (generated from the questionnaire to gain insight into the responses and to provide information to facilitate sampling) will be presented first to provide an overview of the responses. Following this, the qualitative analysis of the interviews will be presented, including thematic maps and detailed illustrations of each theme, including comparisons across the weight categories.

4.1 Questionnaire responses

Initial response, prior to Beat promotion was modest (N<40). Following the promotion by Beat on social media the response rate was high (N=471) and remained high (N=321) on removal of questionnaires that were incomplete or contained errors (i.e. numerical entry issues). Responses were spread across the weight spectrum, age range and diagnostic status (table 2, figures 1.1-1.3)³.

Table 2

Demographic summary of whole sample

<u>Gender</u>	<u>Number</u>	<u>BMI range</u>	<u>Age range</u>
Female	307	12.5-57.7	18-59
Male	12	16.2-43.9	19-50
Non-binary	2	17-43.5	22-23
Total	321		

The low number of responses from males (3.7% within the current participant group) is not unexpected as recorded prevalence of DE in males has historically been much lower than prevalence in females (Jones & Morgan, 2010). The proportion of responses from

³ The promotion by Beat does bias the sample towards those who have recognition of their own DE and are actively seeking help and support, at the very least through the B-eat website. It is acknowledged that this will not reflect the level of DE in the wider population however, the representation across the weight spectrum allows for insight into the research question, whilst acknowledging the degree of bias in the sample.

males did not meet current prevalence estimates (11%, Beat, 2018) so male data was not included.

4.1.1 Diagnostic complexity

Participants were asked what ED diagnoses they had received as well as any other mental health diagnoses. The results showed a complex picture of diagnoses which were analysed with regard to the BMI weight categories.

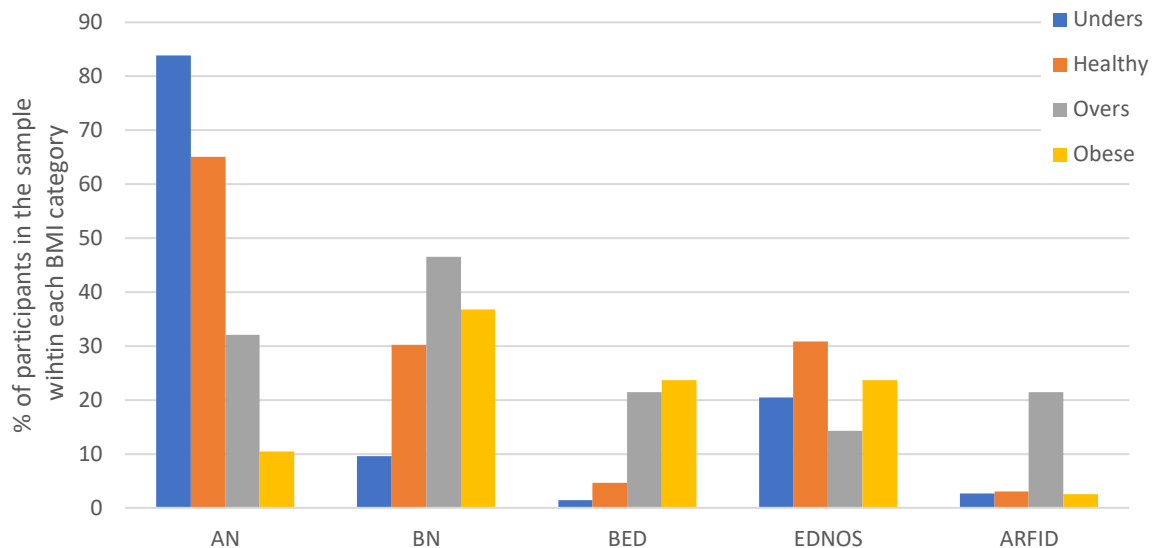


Figure 1.1 Percentage of participants within each BMI category by specific ED diagnosis⁴

Although the majority of the diagnoses of AN were found within the ‘underweight’ category this diagnosis was also found across the other weight categories; BN diagnoses were more commonly found across three weight categories, ‘healthy’, ‘over’ and ‘obese’; BED was most commonly found in the ‘over’ and ‘obese’ weight categories; EDNOS was spread across the weight categories; ARFID was found mostly in the ‘over’ category.

⁴ AN – Anorexia Nervosa; BN – Bulimia Nervosa; BED – Binge Eating Disorder; EDNOS – Eating Disorder Not otherwise Specified; ARFID – Avoidant and Restrictive Food Intake Disorder

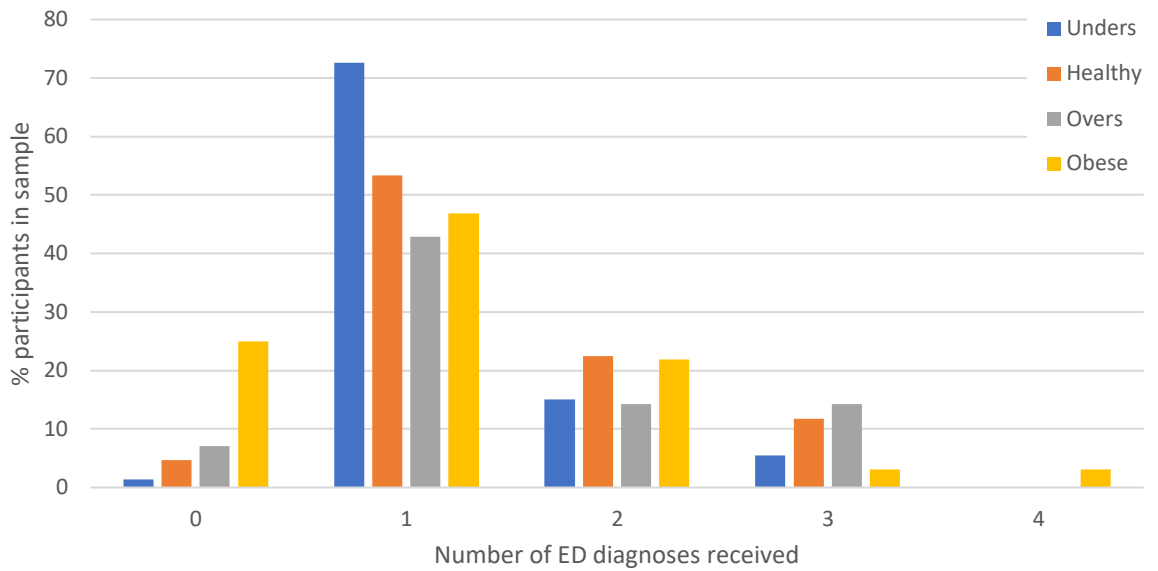


Figure 1.2 Percentage of participants in receipt of multiple ED diagnoses

The 'obese' weight category was the category least likely to be in receipt of any ED diagnosis; the majority of those in the 'under' and 'healthy' weight categories were in receipt of just one ED diagnosis. The overall picture suggests that individuals presenting as 'underweight' are deemed more 'straight forward' in diagnostic terms (however, it is uncertain whether individuals' diagnostic experience provides an accurate representation of their challenges in terms of EDs and mental health).

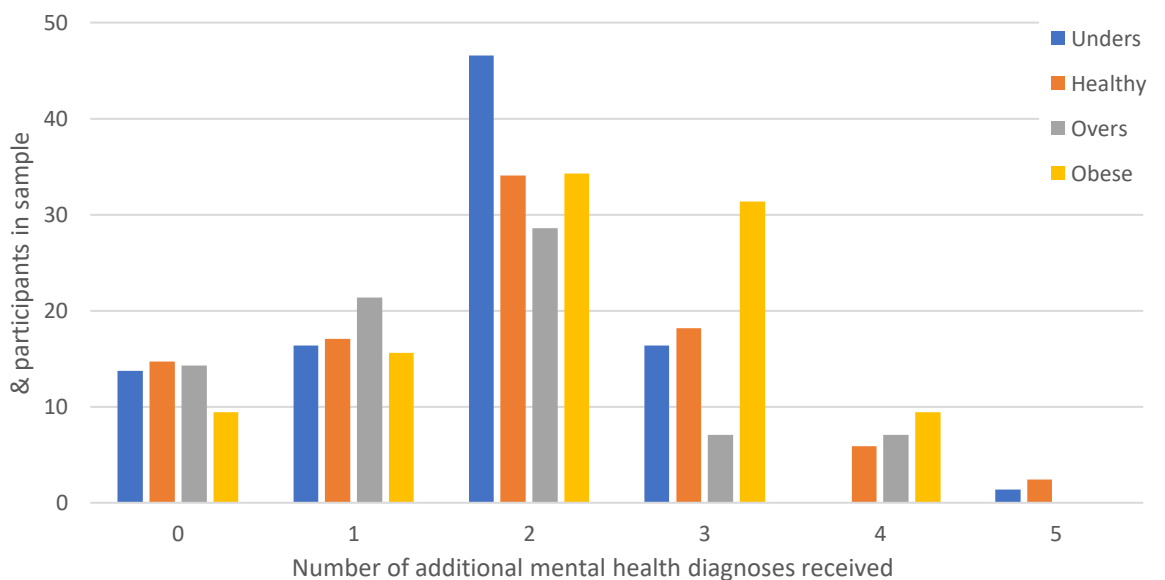


Figure 1.3 Percentage of participants in receipt of additional diagnoses

Examining the numbers of additional diagnoses received by participants (e.g. anxiety, depression etc.) it was more common for participants to have received multiple

diagnoses in addition to their ED, suggesting that co-morbidity is the ‘rule’ rather than the exception (ref. section 2.2.4).

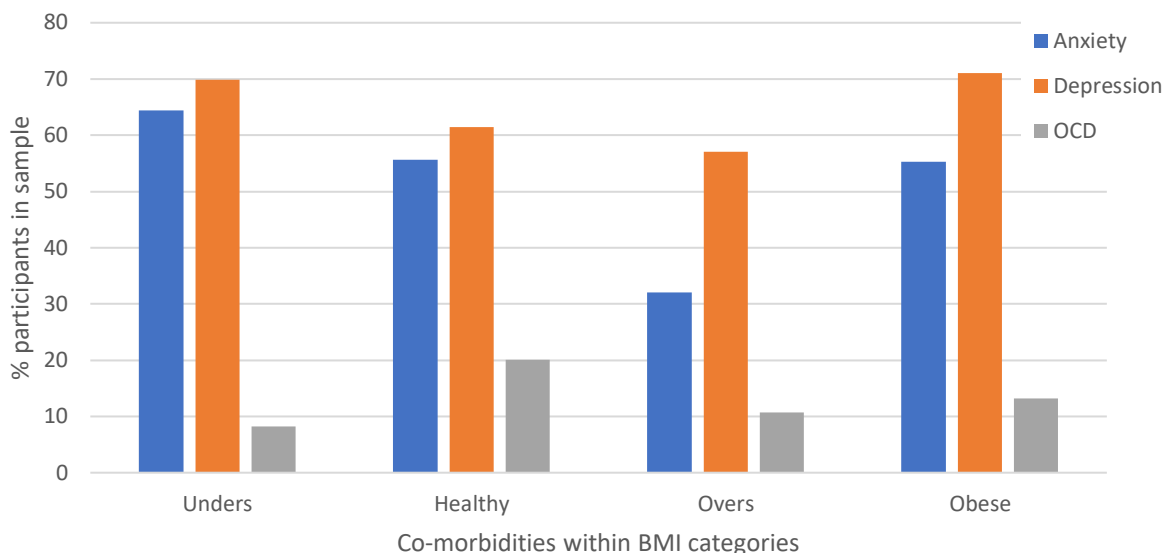


Figure 1.4 Percentage of participants with the most common co-morbidities

Anxiety, Depression and OCD are the most common co-morbidities and these impacted participants across the weight categories at very similar levels.

A similar analysis was then conducted regarding treatments to determine patterns.

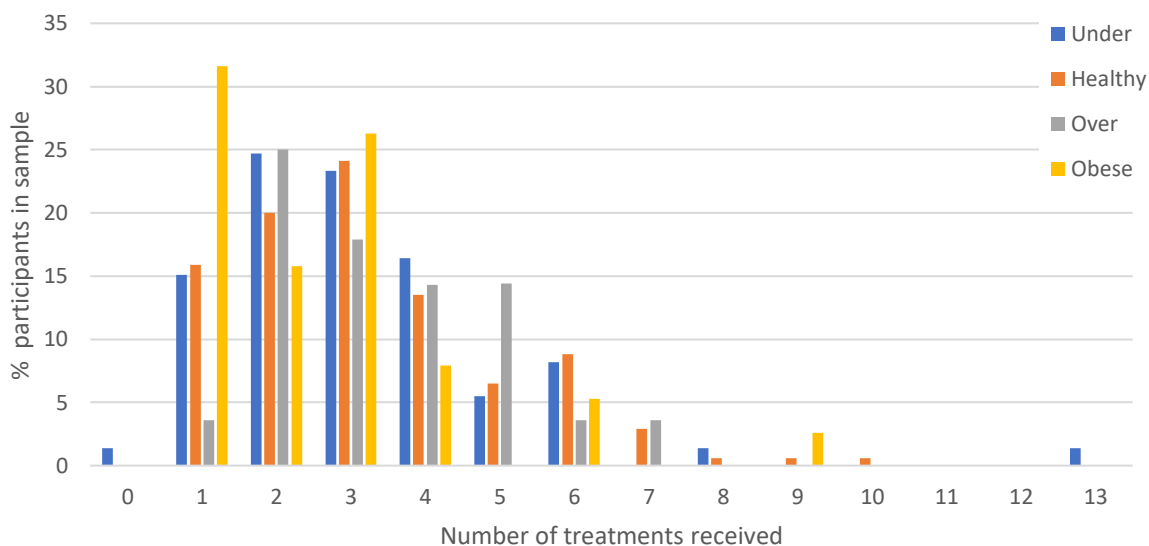


Figure 1.5 Percentage of participants receiving treatments⁵

⁵ The term ‘treatment’ was used in a broad way to include peer-support groups as well as formalised treatment programmes and one-to-one support from different HCPs - see appendix 8.10 for a complete list of treatments.

It is clear from these analyses that the participants represented a high degree of complexity both in terms of diagnosis (ref. section 2.2.4) and in terms of treatment.

4.2 Sampling across the weight spectrum

The responses were separated into weight categories using the NHS BMI bandings (table 3).

Table 3

NHS BMI bandings

<u>BMI category</u>	<u>BMI</u>
Underweight	<18.5
Healthy weight	18.5-24.9
Overweight	25.0-29.9
Obese	<30

Analysis of each weight category was conducted in order to facilitate a stratified random sampling approach (section 3.4.2) that would represent the categories. Each weight category was distinct in terms of frequencies, diagnosis and treatment complexity (appendix 8.9, tables and frequency graphs).

4.2.1.1 Age of onset

A basic analysis was conducted of the self-identified age of onset (Avg. AO) of DE for interview participants.

Average age of onset was 14 (15 when including outliers).

This is consistent with the findings from Beat (2015) that 62% of cases identified onset as occurring under the age of 16.

Examining across the weight categories:

Table 4

Average age of onset of disordered eating across the weight spectrum⁶

<u>Under</u>	<u>Healthy</u>	<u>Over</u>	<u>Obese</u>
14 (19*)	14	13	14 (12*)

Numbers with * include outliers

4.3 Qualitative analysis

Due to a high response rate at the questionnaire stage and the decision to run more interviews than originally intended to better represent the participant groups (appendix 8.4 & section 3.4.2), a change of approach was taken at the analysis stage (appendix 8.7) with the framework of contexts used through which to examine the experiences of the participants: family, healthcare, social-formal (i.e. school, university, work), and social-informal (i.e. friends, wider society, media) as well as views on potential improvements. In addition to exploring themes across these contexts, an additional context of 'self' was included to encompass the construction of understanding self across the experiences. Thematic maps were produced for each of the context themes.

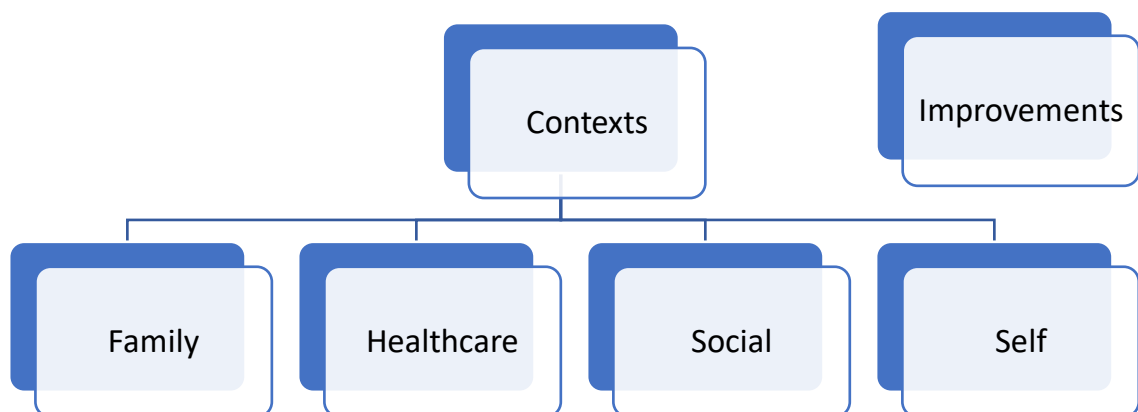


Figure 2: Map of contexts (underpinning the interview schedule)

⁶ The weight categories are for current weight presentations and it should be noted that some individuals' weights had fluctuated across the extremes across time. Regardless of current weight presentation, we can see that the age of onset for females was consistent. Individuals' who identified a later onset, in many cases, reflected that the origins may have occurred earlier than the actual behavioural elements.

Quotes are used throughout as illustrations of the themes within the narratives. To ensure that the participants' anonymity was protected, a cautious approach was taken, removing terms or reference to people/place or phrases that have the potential to identify.

4.3.1 Family

This context was central to all participants, however there was some variation in the experiences. Family context was defined as parents, siblings and extended family. Three themes were identified: The causal narrative; Responses; The recovery role.

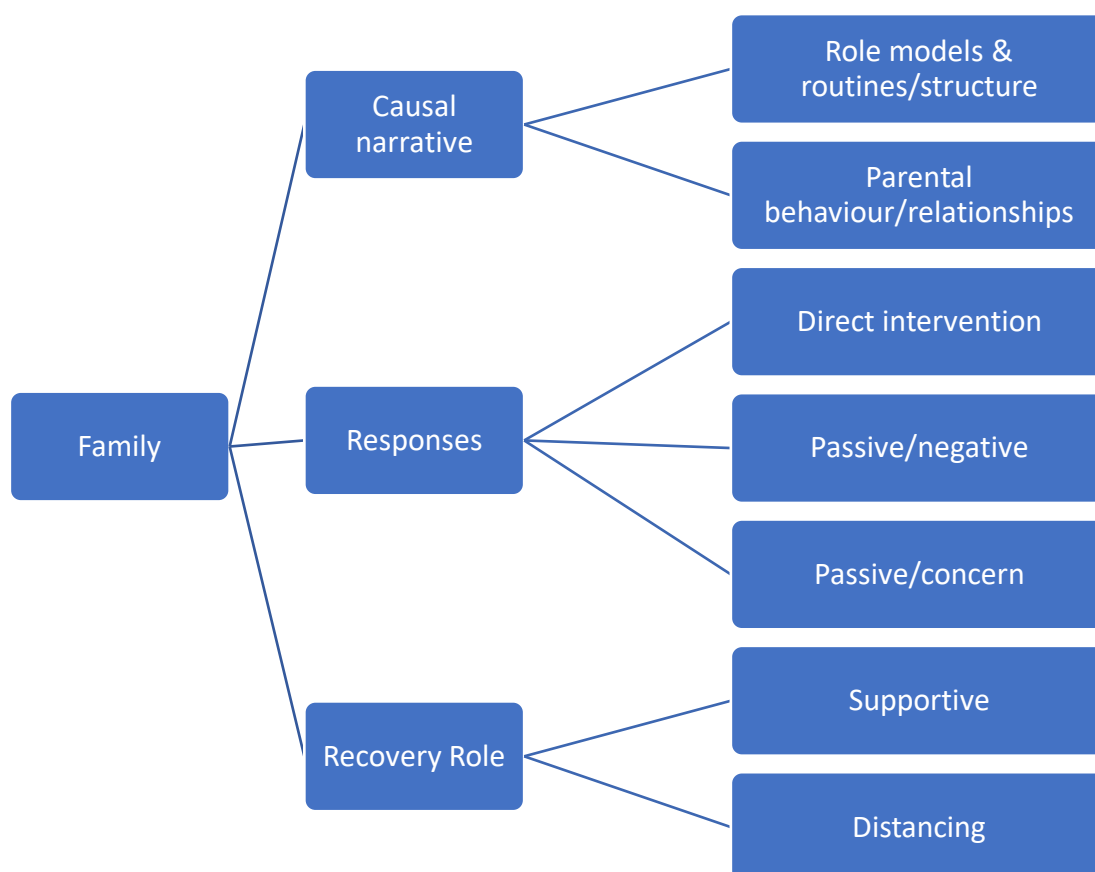


Figure 3: Thematic map for the context of family

4.3.1.1 The causal narrative.

For the majority of participants, there was an awareness of issues around food and weight starting around the pre-pubertal period while they were living at home. The role of the family environment was cited as significant in causal terms in two main ways – role-models and the structure/routine of meals however, there were some instances where challenging or difficult parental behaviour/relationships were cited as significant.

Role models and structure/routine: Where individuals had experienced a parent or both parents expressing discontent with their weight, taking part in various diets, skipping meals, eating different/less food than the child at meal-times and so on, this was cited as playing a role in the development of ideas around weight, giving the subject of body weight and body-image a greater emphasis. This was seen as a predisposing factor.

"I come from a family where um weight n dieting has always been a main focus" ('Hayley')

"My mum used to do every diet under the sun, she was always. She would make us big meals but she wouldn't eat with us at all." ('Ashleigh')

"When I was younger I just remember her, <mother> a lot of the time, standing in front of the mirror holding her belly in, crying, and telling, saying how disgusting she was and um always on a new diet and always needing to run or always thinking she was inadequate." ('Naomi')

A lack of routine and structure to meal-times was also seen as playing a key role.

"When I was at home, so, at home we often eat in front of the television on our laps um we don't often coz my Dad works in London, he gets home quite late so we'll well eat at different times" ('Jasmine')

"The eating it was just generally just me that ate at like maybe 5 o'clock maybe Mum wouldn't eat until later an then Dad when he come in from work, it was primarily maybe just me. We all had different mealtimes." ('Teresa')

"Whenever we were at home it's always been a case of like fending for yourself" ('Kelly')

Parental behaviour/relationships: Some participants had experienced challenging relationships with one or both parents, which were seen as significant.

"It became frightening and scary for me. And the fact that I was going to be left with this woman" ('Ashleigh')

"So it's always been quite bad. As long as I can remember. She's just quite a volatile person. And I think, I just seem to like get the brunt of a lot of her anger." ('Lucy') <referring to mother>

However, for many there was a sense of understanding parental behaviour and a desire to be clear that there was no blame being placed but simply an insight regarding how different things had played a role in the development of their DE.

"Coz you know, how, like, they thought they were being supportive" ('Susan')

"I think they felt they were just sorta lettin me be free and get it out ma system <laughs> you know an I don't blame them for that." ('Hayley')

"An I think yeah, I mean that in retro, in retrospect, I obviously know that everyone was doing it in my best interests. But I think that's kinda where, where things started to go a little bit wonky." ('Emily')

The issue of 'blame' within this context is a sensitive one and was not always handled in a way that facilitated better family relations.

"Like, I think they feel blamed for it. So, coz you know how it will say in the research like family can have a, you know, a, and, I've obviously never tried to blame them for it" ('Eve')

The insight regarding the causal role of the family appeared to arise from a distance in terms of time-passed. On moving into adulthood, individuals were able to 'see' how behaviours had impacted on the development of their DE. It suggests that this context may offer opportunities for education and awareness that may reduce the numbers of individuals experiencing DE.

4.3.1.2 Responses

Responses to DE in the home environment varied broadly across three types: Direct intervention, Passive/negative (sometimes involving a 're-frame' of the issue) and passive/concern.

Direct intervention: There were a few participants whose parents responded to evidence of weight-loss (mostly) by taking charge and directing care, arranging and supporting appointments, taking an active role in the support of the individual.

"My mum basically hauled my ass to the doctors, I did not get a choice in that at all" ('Hayley')

"My parents took me, er, to the GP" ('Amber')

Passive/negative: The most common response to DE amongst participants was the passive/negative response which sometimes involved a 're-frame', mostly as 'a phase' (this also occurred in the context of healthcare).

"I was always singled out for this weight problem that I honestly did not have. I realise that now. And I was forced to weigh myself" ('Joanne')

"When I told my mum, and she said she already knew. She said 'oh yeah, I've heard you in the bathroom for years'. And she was like, 'you know I'd buy all that lovely food for us and then it would just end up down the toilet. You're so ungrateful'" ('Ashleigh')

"My parents tried to force me to join weight watchers – I did not want to do that." ('Susan')

Passive/concern: This response was only slightly less common than the passive/negative and appeared as an avoidance of talking about the issues, sometimes through fear of the potential ramifications.

"I remember yanking my jeans up because they were too big and my mum saying 'is there anything you want to tell me' and I said no. So she obviously noticed."
(*'Jasmine'*)

"My mum was always worried about my weight" ('Emily')

The participants whose parents took direct action were individuals who became visibly 'underweight'. Where individuals lost a lot of weight in a short time, but did not fall into the 'underweight' category, even though concern was sometimes expressed, there was no direct intervention and a seeming reluctance to engage in conversation around the issue. The subject of weight emerges from this as one of taboo, which is in ironic contrast to the very public ways that weight expectations and judgements are made clear in wider society.

4.3.1.3 The recovery role

The role that parents played in the recovery process fell into two categories – supportive or distancing.

Supportive: For participants whose families were supportive, that support was developed through increasing the families' understanding of the issues and how to support the individual.

"I lost myself for like a long time and I couldn't remember who I was. I just was an eating disorder so someone needed to keep reminding me this is who I am and whatever." (*'Naomi'*) <speaking of mother and sister>

"...for <the therapist> to then sort of explain more how it works, an my mum read some books as well, some books about em you know having a child with a, with an eating disorder, an I think they helped her understand it as well" (*'Amber'*)

Interviewer: So the hospital provided support for your parents – was that helpful?
"Yeah coz like er they maybe they understood it a bit better, an understood what to say, what not to say" (*'Teresa'*)

Distancing: For the individuals that found it better to distance themselves from the parents/family in order to facilitate their own recovery, it was felt that the family would not be able to or were unwilling to understand and offer support – distancing was a way of providing safety. Sometimes the distancing was very permanent.

"I have avoided going home at times when I am not feeling confident about my weight." (*'Grace'*)

Interviewer: Do you think that they'd actually understand about the...

"No. An I think that's why I haven't told them in a sense?" (*'Susan'*)

"I told my mum I'd never see her again. An I haven't spoken to her since. ... its' a toxic relationship and it makes me, and it made me ill." (*'Ashleigh'*)

Scrutinising the data further, the individuals who did not cite their family as causal in any way were those who were diagnosed with AN in their teens, whose families took direct action to support the individual following extreme weight-loss. Taken in the context of how weight impacts on responses, this suggests that the weight-loss/'underweight' had a role to play in the responses of those families.

Another, perhaps less surprising pattern was also apparent in the data connecting the families' responses to the DE and their role subsequently in recovery. Families who took direct action or who had a passive/concerned response played a supporting role in recovery. Families who had a passive/negative response were distanced.

These patterns were apparent across the weight categories.

4.3.1.4 Regarding 'blame'

Whilst acknowledging the role of parental and familial influence, the majority of participants did not assign these behaviours to malice or intent but rather framed the behaviours within the context of the era they were raised, misplaced good intentions, or the impact of previous generations playing out. 'Not blaming' was important for many – the narrative emphasis was on understanding. For participants whose families had been able to benefit from input from services, there was also an appreciation of their willingness to adapt in order to support them better.

Sadly, for some, this was not possible and distancing themselves from their families was an important part of their recovery process.

4.3.2 Healthcare

With or without diagnosis or treatment, experiences with healthcare services was an important part of participants journeys with their DE. Four themes were apparent in the data for this context: Getting there; Not being understood; Acknowledgement/validation; Weight and perceptions.

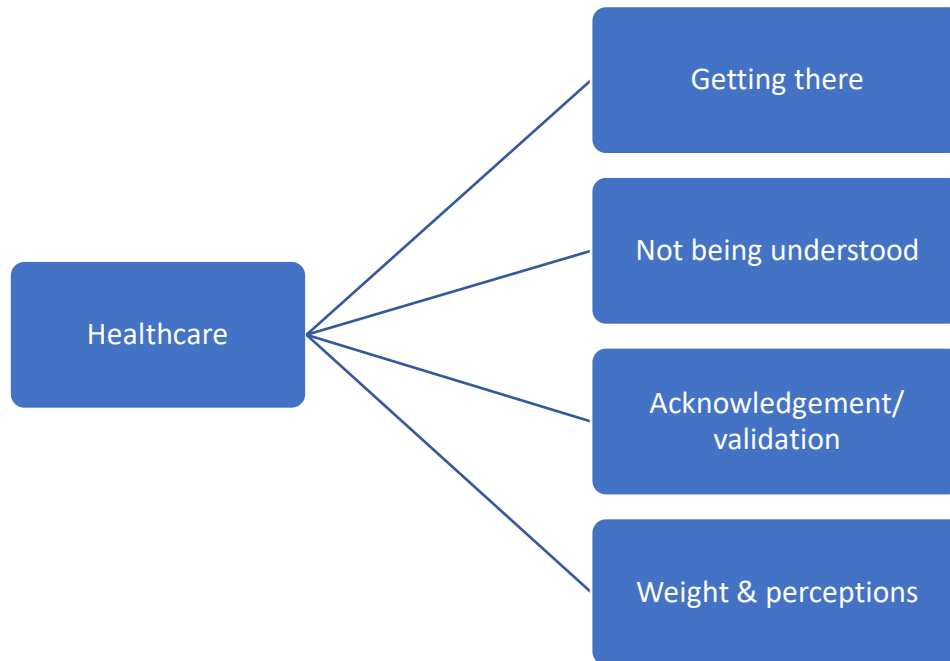


Figure 4: Thematic map for the context of healthcare

4.3.2.1 Getting there

Individuals either sought engagement with services themselves, were ‘picked up’ due to specific medical events/concerns or were encouraged/supported to go by their families (section 4.2.1.2). The difficulty in getting to the point of seeing their GP was acknowledged by a number of participants and fear regarding the anticipated response of the HCP also acted as a barrier in some instances. For many, the issue of ‘deserving’ treatment played a role as well as a linked issue around not considering themselves ‘ill enough’.

“I was relieved that she hadn’t laughed me out of there, in a sense, um, but I was really pissed off because it had taken a hell of a lot of guts to to even make the appointment let alone turn up, let alone say how I felt” (‘Emily’) <on being told by the GP that they would fall rather ‘far down the list’ for treatment>

“When I went to the GP when I was 16 and I got dismissed that’s why I didn’t go back until things were like dreadful... I think like because in my head then I was like, well I can’t like I can’t see my GP until I’m underweight cos of what happened before. I know it’s not really a problem until I’m underweight.” (‘Lucy’)

“You know it took a lot a lot of guts to go in there actually, to say it out loud to a stranger um especially thinking he might be able to help” (‘Ashleigh’)

The concerns from participants evidenced not only the issues of stigma and shame regarding DE/EDs, but also the concerns that their weight would influence the views of the HCP.

4.3.2.2 Not being understood

When participants talked about seeking help, there was a strong sense of wanting clarity and explanation. For many people there was confusion over what was going on and the HCP was ‘the source’ of information that would enable the individual to navigate to appropriate treatment. There was quite a lot of confusion at these points in the narratives whereby responses (from HCPs) varied enormously, with many participants experiencing a lack of understanding or a ‘re-framing’ of their issues.

“The time that I, the brief time I did see someone, was after I stopped eating in hospital for about two months. I just didn’t eat. And that’s when I saw someone. But I, like, I feel like, I won’t see someone with my bulimia probably <laughs> because it’s not seen as bad enough or something.” (‘Eve’) <only contact with ED services followed period of restriction>

“I went to my doctor and said, the first time ever, I said look, I need to speak to someone because I’ve had an eating disorder for nearly 20 odd years and I’m, I just really, I need to find a way of stopping this because you know I’m worried that I’m gonna get ill An um, he just said well you know you look perfectly ok to me. An I said what does that mean? And he said, well we need to weigh you, and I said oh no I’m not doing it for weight, and he said well why else would you be doing it?” (‘Ashleigh’)

“When I was 15 my Mum took me to the doctor and he just said oh she’s just going through that teenage stage where she just wants to lose a bit of weight. I think she looks great <laughs>” (‘Naomi’)

These experiences suggest that the patient’s appearance was playing a significant role in the judgements of the HCPs such that the underlying distress was not acknowledged.

4.3.2.3 Acknowledgement/validation

The ‘gate-keeper’ power of the HCP was clear in the narratives of many participants. Where an issue was not acknowledged/validated by the GP or HCPs, there was an on-going experience of confusion and, in some cases, a loss of hope that anything would change. Where individuals had received acknowledgement, often in the form of a

diagnosis, there was a sense of relief but also a sense of being able to work 'with' HCPs to move forward, as well as moving away from a feeling of isolation; the validation itself appearing to provide hope and momentum.

"Where I felt sort of invalidated is that I've told them an they've just sort of ignored it and not doing anything about it or mentioned it again." ('Natalia')

"I told them <the GP> that I thought I was maybe struggling with an eating disorder because I was restricting and I know it sounds stupid but I'd like a voice in my head that was telling us that I was disgusting an I was fat an not to eat an not to do this. Interviewer Ok. And what did your GP say?"

"Could you not just get over it. It wasn't until about the sixth time that I went to the GP that they actually referred us to the clinic in the area but I had to keep going back an like I got to the stage where mum refused to move from the room until they actually got us proper help. Because apparently my BMI was still at a healthy weight so they didn't really do anything for us" ('Teresa')

"Because up until then I felt like I was just on my own, fighting in the dark. And I really needed someone to actually sit down and go actually, do you know what this is, what it is and this is what we need to do." ('Hayley') <on receiving a diagnosis of anorexia>

The power of the HCP in these consult experiences is clear. Without acknowledgement, the patient's distress typically continued.

4.3.2.4 Weight and perceptions

The role of weight in having the distress of DE accepted was common across participants' narratives. Regardless of the nature of the diagnosis, weight was felt to have been significant in exchanges with HCPs.

"I saw the psychiatrist, an at that point, I think my BMI was like 18.6, an he was like look, you're BMI's 18.6, it's not like less than 18.5, so there's not really a problem here... Like if my starting weight had been lower I think they'd have taken it a lot more seriously but I was still really struggling" ('Lucy')

"They said that I couldn't get any help because of my BMI" ('Naomi')

"My life turned around my weight. And over-exercising. Either it was about binges or it was about restricting and I think, and body image issues and so somehow I think it was really missed. I think if my weight had been much higher or much lower perhaps it would have been more attention to what I think was more a cause than a symptom" ('Joanne')

Scrutinizing the data further, there appeared to be some distinction between the weight categories in that individuals with AN were likely to be taken to healthcare or to be 'picked up' due to health events whereas across the other weight categories there was a greater tendency to seek help by themselves, usually after many years of

struggling with DE. No-one within the higher BMI category (classed as 'obese') was referred for ED treatment although some self-referred/sought private healthcare and were treated. There appeared to be more of a struggle to get referrals at anything other than 'underweight' although those at 'underweight' were often monitored for a period prior to referral, resulting in a worsening of their symptoms.

Almost all participants felt the delays to referral played a role in, if not worsening their condition, unnecessarily prolonging their ED/DE experiences.

There were very few narratives of successful treatment regarding ED/DE across the entire data set. Those with a positive experience of treatment(s) felt that they were recovered; there were three instances where individuals had received no treatment but were in a good position in recovery-terms (two feeling recovered and one partially recovered). Those who had received some treatment or no treatment mostly felt they were either not recovered or partially recovered.

4.3.2.5 Participants views of the current healthcare system

This section of the analysis does not wish in any way to engage in 'GP/ HCP-bashing' – this would neither be an accurate representation of the participants' voices or a constructive exercise. However, one thing was clear across the complex and varied narratives for the vast majority of participants: there were multiple engagements with HCPs before any action was taken, representing a series of 'missed opportunities' in many instances.

The initial triage point for most DE was the GP. GP's roles have become incredibly complex and challenging with multiple expectations being placed on the (brief) appointments that they conduct with patients. There was a clear recognition of the pressures on GPs, the system within which they work as well as acknowledgement of the wider pressures on the NHS as a whole. Many participants sought to mitigate poor responses from healthcare professionals in the light of these pressures.

Participants narratives evidenced an awareness of a "postcode lottery" in terms of service provision which, again, was understood in terms of finance restrictions on the NHS. The lack of connection and differing approaches between different services within the health service was also a cause of concern and delays in accessing treatment, with participants being passed from one service to another before any action was taken, in some instances with no action being taken.

4.3.3 Social-formal

This context includes schools, colleges, university and workplaces. The participants' narratives were varied with some childhood/teenage onset but some adult onset/realisation (work being the social-formal in these instances), as such, the response from the relevant 'formal' environment was considered in one category.

The themes were: getting noticed; getting involved (officially); being supportive.

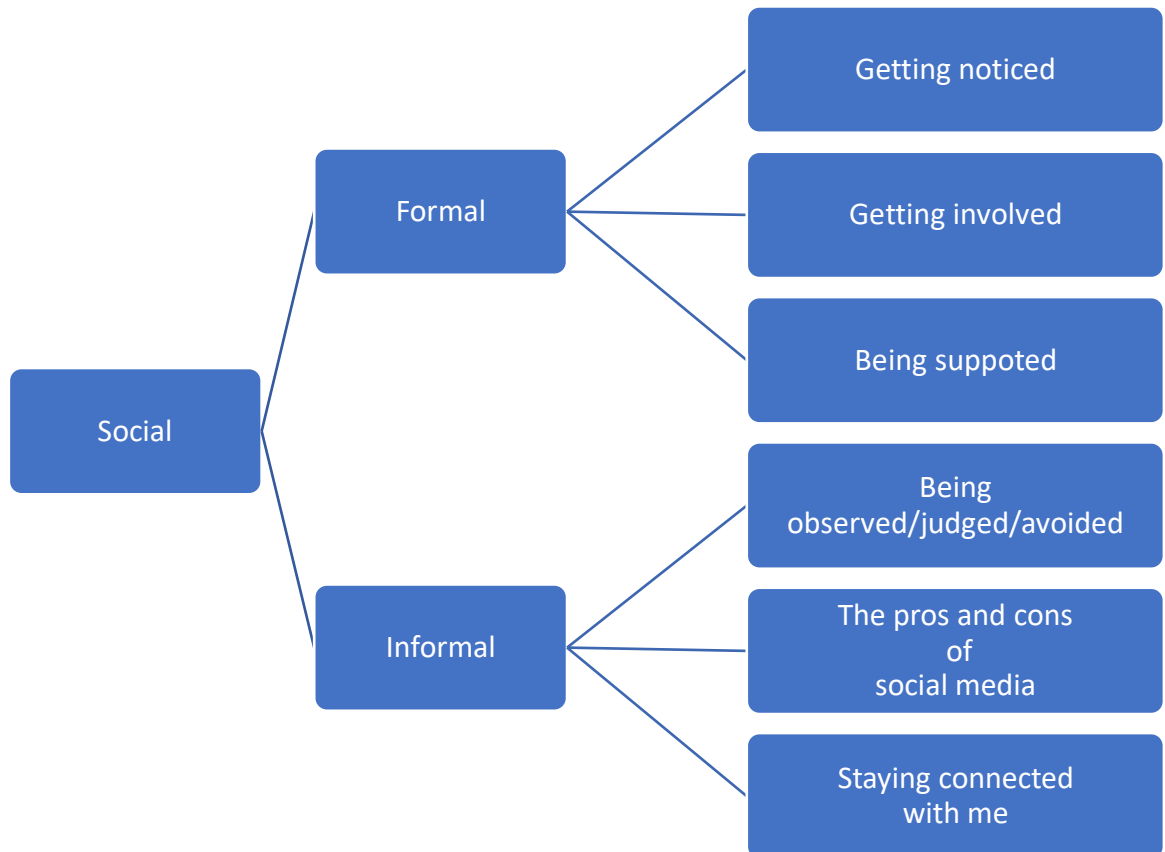


Figure 5: Thematic map for the social context (formal and informal)

4.3.3.1 Getting noticed

The data set was spread across a broad age range, representing a significant shift in school support services and approaches. Whereas currently, many secondary schools have developed their own pastoral care departments, this was not formalised in many schools in the past, with pastoral care provided in an ad hoc, informal way. In general, there was little acknowledgement of distress within schools - not being noticed was usually attributed to their appearance of functioning well within school being taken as an indication of the child/teenager being well. There were no instances of universities or work environments noting any issues for any participants. Some participants had

informed their school/university/work about their issues (either themselves or their parents).

“No-one in the school knew I was doing it the whole time I was there so I got away with it” (‘Ashleigh’)

“When I was at school, if you were doing well then like ‘oh you must be fine’... if someone had sat down and said look, we’re quite worried about you, I’d probably, would’ve sort of thought about it more. I probably would’ve got help, then. Um probably wouldn’t be like still sort of 26 in like the ED service.” (‘Susan’)

“I don’t think I was ever at the point when I was at school where I looked unhealthy. Um. However, I know a teacher, I’d been to a teacher in confidence but I hadn’t, I I wasn’t sleeping at home I I had like quite bad insomnia for, on the run up to my A’levels n I went through a lot of stress. N n she’s now said to me in retrospect that she could see it coming. I don’t know how she could say that. Em. But yeh she could see that I was obviously struggling but she never really did anything else, she didn’t get in, I mean when I told my mum that, I obviously said this to her, mum was like, well why did she not get in contact with me? And maybe she should of, n, coz, I wasn’t right.” (‘Amber’)

“In terms of the school, I had those problems and I had Mum in the school there with the headmistress saying look this is why she needs to do this because she’s overweight blah blah blah an then you also have my sister who was anorexic at school at the same time, at the same school. So for two of us, in the same family, I think that someone <laughs> would have noticed one of us <laughs>” (‘Emily’)

4.3.3.2 Getting involved

This was defined as informing the parents or offering some direct support within the organisation. This did not occur much across the data set. There were some instances though where the school became very involved and liaised with the parents and healthcare in order to support the individual.

“They were never pushy, they were never like um intrusive, they were always asking they would ask like are you ok. Rather than what are you doing to yourself type thing so, how you would treat me if I wasn’t ill type thing? But they just kind of accepted it and I guess they kind of knew that as other people were there to deal with it and it wasn’t their place to try and help it was just to make sure that I was comfortable I suppose? Within the classroom? And yeah, they were great.” (‘Kelly’)

“Very early on when I was ten and starting to purge a teacher approached me and then sent me to the school doctor Then nothing for a while until the anorexia and I lost so much weight that teachers started to notice and they sent me to the school doctor and, I will always remember this, ‘oh no you’re fine but if you want to come and see me privately just tell your parents it’s £100 an hour’ or something which was quite shocking <laughs>” (‘Joanne’)

“The school were already kind of aware of what was going on because they’d tried to phone my parents an talk to them about it a few months before but my mum didn’t believe them.” (‘Lucy’)

4.3.3.3 Being supportive

This appeared to be handled informally almost as much as official action was taken, often offered by a particular staff member who had noticed the issues. The workplace itself was identified as unhelpful regarding supporting healthy eating behaviours by two participants.

“They were as supportive as they could be but I don’t really know if there’s anything else really they could’ve done. I suppose maybe they could’ve offered me um you know counselling or something like that but it just wasn’t available.” (‘Natalia’)

“I was working 90/100 hour weeks and I basically, you kind of, at that point decide that ‘I’m not going to get up in time to have breakfast because it’s another 15 minutes in bed that I could have’. So I wouldn’t eat breakfast. My natural break in the day came at about 4 o’clock um so I wouldn’t have eaten lunch. I would get through to 4 o’clock, by which point the canteen was closed, there was no food. The only food that was available was from the shop um and so I would go and grab a pasty and a bag of crisps so I would go and buy maybe a sandwich.” (‘Grace’)

“She used to let me come into her classroom and she’d make me a low calorie hot chocolate. She was so lovely” (‘Naomi’)

In general terms, there was not a lot of response/action across this category; what there was showed an interesting picture across the weight categories. Those in the higher weight category (classed as ‘obese’) reported receiving no recognition however individuals who had lost a lot of weight rapidly were sometimes picked up by schools even when they had not become visibly ‘underweight’. Action was taken more in these instances than in the ‘underweight’ category. There were clearly issues whereby an appearance of functionality/coping with pressures was equated with the individual not having any problems that required support.

4.3.3.4 On the influence of the military

Across the data set the issue of the impact of time spent in the armed services was noted by approximately 20% of participants, not just by those who had been in service but also by participants who had parents who had spent time in one of the armed services.

“You can always, what we called ‘doubled-up’, which is have two puddings. And nobody’s checking what you’ve eaten” (‘Grace’)

“He’s sort of like ex-military. Really, he was like probably, like, late teenager he was and then like he’d put on weight when he came out and sort of went to sort of civvy street as they call it, so he kind of lost that structure I guess. Whereas yeah coz he’d been in since he was like 16. They tell you when to eat” (‘Susan’) <regarding father>

4.3.4 Social-informal

This context is used to include the media as well as friendships and informal social settings. The role of friends in noting and helping get treatment was negligible however the role in recovery was important. There was very little comment about the role of media in terms of imposing or stressing the 'thin-ideal'- origins of DE were almost exclusively around management of stress, emotion and difficult situations.

Themes were being observed and judged; the pros and cons of social media/media; staying connected.

4.3.4.1 Being observed, judged and avoided

There were a variety of experiences in terms of how friends responded to evidence of DE/ED ranging from friends being oblivious to any issues, through distancing and rejection, to solidarity with the individual. There was a clear sense of 'self-altered' as an explanation for any distancing but also an appreciation of friends who did stay connected.

"They kinda just distanced themselves from us like it was trying like oh do you wanna go out and it was like we're busy an that's never helped us coz a felt very alone kind of thing" ('Teresa')

"I've had so many friends in so many different friendship groups it never, I don't think anyone ever noticed anything was wrong" ('Emily')

"I lost touch with quite a lot of friends because I think they just found it really hard to be around me because again I wasn't the person that they were initially friends with erm a lot of them have still tried to support me." ('Amber')

4.3.4.2 The pros and cons of social media/media

The concept of the 'thin ideal' being portrayed and enforced by media, fashion and society is central to a lot of beliefs about the 'cult of thinness' and how that related to EDs. The idea that 'the media made me do it' was not apparent across most narratives although there were notable instances where this was the case. There was a clear sense of the potential for media, social media in particular, to be a force for change, especially with the rise of the body positivity movement. However, there was caution expressed in terms of the 'darker side' of social media, with specific reference to 'pro-ana' sites/feeds and also the portrayal of EDs as 'young underweight middle-class females'.

"That article in that magazine was dangerous because it glorified it" ('Ashleigh')

"My recovery three years ago really started around listening to podcasts and kind of hearing about people who had recovered and learning it was possible. Because the

narrative of recovery doesn't exist for people with bulimia and binge eating, it only exists for people with anorexia." ('Joanne')

"It is better than it was but I think, I dunno I think, because, there's a lot more sort of like on social media I think, you can always be like exposed to it a lot more. So yes it's almost like in what way you take certain things. An it could be seen as positive or, I think because with the rise of social media it's a lot easier for people, or those things that are banned, but sort of like pro-ana sites, I know a lot of people who still use those. So, it's kinda like well there is a good side of things, that coz there's a lot more body positivity stuff, things an there's a lot of more easily accessible horrible things as well?" ('Susan')

4.3.4.3 Staying connected with 'me'

Individuals who felt they had received support from those around them felt that the friends/family had a connection with their 'original' self, who they were without the illness and were able to remind and support them to pursue the interests they had beyond the DE.

"They've always come by my side, they've never been like, you need to do this or you need to do that or like whatever. They've always been like so supportive and said the right thing" ('Naomi')

"I'll tell her the truth or the hard thing even when it's not what she wants to hear um so she's been my complete rock throughout all of this. And it's good to have someone there who understands coz they've been through it too" ('Jasmine')

"Somehow or other I still managed to keep my friendship group. I don't know how. I guess it was just that coz we'd know each other, again coz we're from quite a rural place, we'd know each other since we were at primary school" ('Kelly')

4.3.5 Self

'Self-as-context' is a term taken from Acceptance and Commitment Therapy (e.g. Harris, 2009) and explains the ability to, experiences of and efforts made to understand self.

Across the participants' narratives there was a clear theme regarding the importance of understanding self and their journeys, to make meaning of their experiences and to gain clarity in terms of moving forwards.

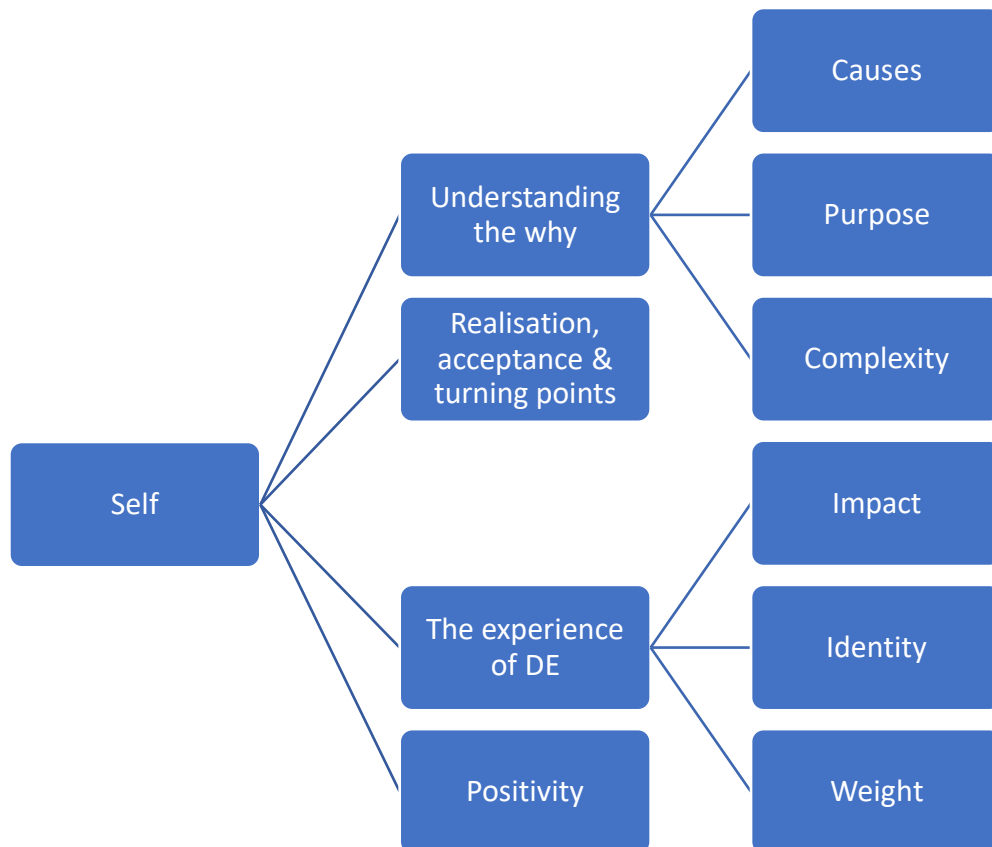


Figure 6: Thematic map for the context of self

4.3.5.1 Understanding the why

This theme centred around participants seeking to understand why they had developed DE and what purpose it served. As participants identified differently in terms of 'recovered status' some had developed a comprehensive understanding whereas others were still seeking understanding. Understanding why, however, was an important part of recovery for participants and, in some instances, had enabled them to take action to avoid the same pressures occurring again. Within the theme, three sub-themes were identified: Causes ('something about me' and the behaviour trap); Purpose (coping and control); complexity.

Causes: A number of participants felt that their DE had always been there and was fundamental to who they were. This narrative also extended into recovery with some participants feeling that the DE or the tendency to use DE behaviours would always be there.

"I think I was like it also felt kind of familiar so I think those thoughts must have been in my brain anyway." ('Jasmine')

"I've always been a little bit different" ('Kelly')

"I think it's been inherent within me for a while" ('Naomi')

In addition to the causal element of 'self' and the family there was an understanding that the causes were complex. For some there was an accumulation of a number of different events that, they felt, had led to them 'breaking'.

"It was almost like I was brushing it under the carpet and pushing on and pushing on an pushing on um desperate to keep going almost and then it just, there was a point where I just went, I'm broken and it kind of, the realisation just hit me all at once when I went, 'I'm broken'" ('Zoe')

"An then, just broke, at that point, just completely broke." ('Hayley')

"I was getting bullied in school um and also we moved, we were moving in sort of in the middle of my school year when I turned 14 and so that caused a lot of stress as well so I think the combination of those two things and also um sort of comments... from my Mum and like her diets and stuff I think that all started it." ('Eve')

"there was a lot going on" ('Natalia')

Further, there was an issue whereby the DE behaviours themselves 'trapped' the individual – once the behaviour had started it was hard to stop and the longer it went on the harder it was.

"I started kind of changing what I ate, um trying to eat a bit healthier, trying to avoid certain foods, um and I guess that kind of very quickly spiralled out of control" ('Natalia')

"I can justify that first bite to myself. Absolutely justify. You deserve it. You've had a crap day. You feel rubbish. You deserve this. It's a it's a treat it's all of those you know positive things. Well I'll have the first bite and then I won't stop. And I can't and I can't stop." ('Grace')

"I think it all sort of became, became a habit. You're doing it every day. Stressful situations yes would mean 6 or 7 times a day um because you get sort of a you're enjoy the feeling that it gives you." ('Ashleigh')

"I didn't really know what I was doing. It's it was like um I think the one thing that I always kind of like hear that people who binge eat is it's like you're in like you go into like auto-pilot you're not really present. It's really strange. Um. So I couldn't even tell you what I used to think about when I was sat there in my car." ('Emily')

For those who had gone to a very low weight there was also what I term as an ‘anorexic hangover’ whereby even if weight had not been an issue to begin with, the regaining of the weight *became* an issue that, in itself, presented additional challenges to recovery.

Purpose: The word ‘control’ came up across the data set. The DE behaviours provided a means of feeling a sense of control where life was chaotic

“I think it was also a form of control with regards to my mum being so controlling and having that sort of, the way that she treated me and the way that she was. The way she made me feel these things that made me do stuff to my body. I think it was something that I was like this is mine. You can’t do anything with it. So it was that sort of thing of I am in charge of this and I’ll do it and no-one knows about it.” (‘Ashleigh’)

“That’s usually triggered by, <pause, sigh> some sort of stress at work, emotions, um, things that er I don’t know I almost should be the other way round, I almost should be anorexic, it’s about exerting control” (‘Grace’)

“Yeah because it’s you know control felt good. Coz I could have control over this food I could have control over how I looked I could have control about how I felt an I didn’t want control to, but I didn’t want to feel out of control.” (53707)

“I still slip. I think it’s just when I feel like something is going wrong or or I’m not in charge or something I’m not in control of something an that it’s just a something I can do that is my decision it’s completely my decision an I will always choose, well, I say I’ll always choose to give in to it well that’s not true now but I kind of kidded myself previously into thinking it’s my decision. If you see what I mean. But it controlled me rather than me controlling it.” (‘Emily’)

and also served as a coping mechanism for many

“when I explain it to people, anorexia for me is like an addiction. It’s just like bein a drug addict, an alcoholic. In my worst moments when it’s the worst thing I could possibly hold on te I will slip that on like ma favourite jacket. An it’s, an it’s like havin a security blanket that someone’s set light te <laughs> you know what I mean It’s like it’s the worst possible option, but it’s the one that ma mind will click to when I feel really overwhelmed by evrythin” (‘Hayley’)

“what are my coping mechanisms – ways of going and making myself feel better – going and sitting in the supermarket car park and eating – shit. Um <laughs>” (‘Grace’)

“the eating disorder’s always been a way to not deal with what was happening and sometimes it was protecting me – I could not deal. I was not equipped” (‘Joanne’)

But for others, those not far along their recovery journey, there was not yet an understanding as to what the DE behaviour was giving them.

Complexity: This was apparent across the dataset with almost all participants receiving multiple diagnoses (section 4.1.1). This was seen as an issue particularly in terms of a healthcare system that seems to follow a strict path regarding provision of treatments

with treatments being provided for a particular diagnosis and the different diagnoses being placed in a hierarchy in terms of which the HCPs felt was most pressing

“I think if my weight had been much higher or much lower perhaps it would have been more attention to what I think was more a cause than a symptom” (‘Joanne’)

“I just think one perpetuates the other. I think you can’t separate them really because they, the symptoms of borderline include like impulsive behaviour which is an eating disorder so it’s all sort of the same thing” (‘Eve’) <receiving treatment for EUPD but no current monitoring or treatment for the comorbid BN>

“I don’t think eating disorders was a big focus because I had so many other problems” (59707)

“I guess yeah in their training, what they are told is that unless you look like death’s door I don’t know then maybe you’re not, you are ok it just blows my mind that I can sit there with all of these diagnoses of brachycardia and osteoperosis and no periods, hair loss and teeth rotting and low in all of my hormones ... and they still can’t do anything for me, and I’m telling them, it’s not like I’m denying it anymore, I’m going, to be fair I’ve only ever denied having an eating disorder for about 6 months of my life. The rest of it, the other ten and a bit years, I’ve been saying help me.” (‘Naomi’)

The difficulty of getting a diagnosis that made sense was also apparent as well as the desire to be treated as a whole person rather than as a collection of diagnoses

“I think we sort of talked about it but focussing on the individual and not the, a specific diagnosis because different people present in different ways and different diagnosis can sort of add up and you’re not even a person any more <laughs> you’re just a list of diagnoses. So I guess um that would help most coz I I did have one psychiatrist for a while who um who was more rounded in that kind of way and I think that really helped. Um so if more people would, to just sort of step back and think in that way I think it would help.” (‘Eve’)

Individuals presenting at ‘healthy’ or higher weights, even with a variety of the symptoms and additional conditions you could expect to see in an individual with AN at a low weight, struggled to get diagnosis or treatment and saw their weight as a barrier to receiving ED treatment. Preference was given, in treatment terms to other comorbid conditions (e.g. depression or anxiety) and the ED was largely ignored or not considered as being as important for this sub-group. It was very clear that the majority of individuals who presented at anything other than low weight had found it much harder to get a response from HCPs for their DE/ED. The more successful stories came from individuals who had been at a low weight and received treatment but this was not true for all – there were some in the ‘underweight’ category who were still waiting.

4.3.5.2 Realisation, acceptance and turning points

The realisation that their behaviour around food was a problem was prompted in a number of different ways but the shared experience was that there was a period, varying in duration, where they did not realise there was a problem. For some there was a significant medical or unusual occurrence in relation to others.

“Until I had kids I didn’t realise how screwed my diet was <laughs>” (‘Hayley’)

“I was maintaining a low weight for quite a long time primarily with restriction and exercise, um but I’m not sure if I realised it was that much of a problem” (‘Natalia’)

“I remember sort of the point where I realised that something was actually really wrong, um, was when I stopped turning up, I stopped going to, I wouldn’t go to college, an and so instead I would just go to the supermarket an I would just go and buy anythi, like anything, like the most random things, but anything that when I would just walk down the aisles an think oh I fancy that, um, that’s new, I’ll give that a go, an I would just sit in my car and eat an eat for hours and just read a book or you know like because I didn’t want to be doing what I was supposed to be doing, that was the alternative um an then yeah an then I kind of I think one day I just sort of checked myself and I was just like, what the hell are you doing? Like, this isn’t normal.” (‘Emily’)

For others, it was being worn down by the pressure of maintaining the rules around the DE that was getting in the way of living life

“I think I felt so fed up that I was like if I don’t do this now like when am I gonna do it? I think coz it is it is sort of affecting every aspect of your life” (‘Susan’)

“I guess when it comes to the point, it genuinely was a decision of whether or not I was gonna do something to myself, that was gonna stop me from being on this world, in this world, on this planet, um or I wasn’t gonna do that and it was gonna be a, I was gonna get better, I was gonna be there for my family, was gonna, you know, grow up and do all the things I wanted to do, and it genuinely just was that. It was a choice between whether or not I live or whether or not I die and I guess I just chose somehow or other to be here and yeah never looked back since really.” (‘Kelly’)

“I think I started listening to the podcasts about three years ago, I was starting to travel I was kind of reaching, I was in my late 20s and I was reaching a point where there was one thing that was making be deeply unhappy and having some consequences on my life and that was the eating disorder and I couldn’t really avoid it any longer or pretend that I was depressed because I wasn’t depressed anymore, I didn’t need to take medication anymore I didn’t want to hurt myself anymore I just needed to recover from the eating disorder” (‘Joanne’)

There was also an awareness of timing being an important element of treatment.

There were many participants who felt that they had to be ‘ready’ to accept the treatment and that it wasn’t simply a case of being provided with the treatment and them getting better. The cooperative working element of treatment was apparent.

“She saw me one week n sort of, I think she realised, I came to her and said look, I’m really fed up with this now, I really want to get better an I’m getting nowhere. And she sort of, gave me, she put everything into perspective about the amount of food that I needed to eat to get better. And I think mentally I was ready to hear that?” (‘Amber’)

“I wasn’t ready I wasn’t ready to accept that treatment so it’s nothing that they were particularly doing wrong it was because I wasn’t ready to get better. Until I was, um and then yeah.” (‘Kelly’)

The involvement with the patient, the concept of co-production, comes through very clearly from such narratives whereby the patient brings their expertise and self-knowledge to bear in terms of accessing treatment and working with the HCP.

4.3.5.3 The experience of disordered eating

This was one of the most painful themes. It covered the day-to-day experience of living with DE. There were three sub-themes: impact; identity; and weight.

Impact: Across the data set, the way DE dominates and weighs down individuals was apparent. The DE behaviour and thoughts dominated such that it did not allow other thoughts to enter the mind.

“I thought I was crazy because I ate when I had no need to eat I had no want to eat, I didn’t know why I ate. I couldn’t stop it. It was all I thought about you know? It didn’t, n you feel like you’re, you’re actually crazy...it just it just kinda blocks everything out. I just remember feel, afterwards feeling incredibly guilty. Incredibly guilty an thinking why did I do that? I didn’t need that. I feel sick you know I feel so full I feel so full of crap like I could be sick I don’t know why I just did that.” (‘Emily’)

“I’d hate like eating in front of people or like I’d hate going out to a restaurant um an sort of like yeah order food um or like I’d hate going to like the supermarket for almost like the fear of being judged an it’s like it’s crazy but yeah that was sort of like a thing that I had where I always thought, like to be seen out with food” (‘Susan’)

“I have got this internal battle going on really um in terms of well, how ill am I, and what do I deserve what do I need, it’s all very much an internal battle. I’m literally at war with myself.” (‘Zoe’)

Identity: In addition to participants feeling that their tendency to move towards DE was part of who they were, there was also the experience of the DE itself having an identity or of it blocking out the individuals’ feelings of identity with the DE taking them on ‘autopilot’ in what appeared to be, for some, a dissociative experience

“I know that in hindsight it wasn’t me who was doing that it was the part of me that wanted to be ill. That was the part of me that was in the grips of it” (‘Kelly’)

“...a Jekyll and Hyde situation.” (‘Teresa’)

“it’s a strange one because there was so much of me that wanted to get back to my normal self but then obviously the illness was just didn’t want me to n it it didn’t want me to put the weight back on. Um. Even though I knew I did er even though I still do now I still want to get back to who I was n there’s still part of me that’s doesn’t, you know, it panics about putting on the weight.” (‘Amber’)

Weight: How an individual felt about their weight was dependent on their perception of their recovery status. Where individuals had progressed further there was a sense of feeling comfortable with their body, almost of having negotiated a truce or a resolution to internal conflict, whereas those who were still at earlier stages of recovery were less settled on this issue. That an individual’s weight impacted on other aspects of their lives was evident for some participants more than others. There was also a recognition that there may be more challenges but an awareness on how to address this.

“I found that really strange as well because before then I wasn’t bothered, I was happy with the way that I was. I was never really fussed about my weight and after then I was just, after I guess realising or coming to terms with my body how it was and being so thin, I didn’t want that to change if you know what I mean” (‘Kelly’)

“And it almost feels like they’re trying to take the control away from me. So I, like by weighing me then totally monitoring me an then you know obviously depends what they do with that information but yeah. It kind of makes me feel almost vulnerable to them doing something or saying something” (‘Zoe’)

“...there’s one side of fat shaming but actually there’s also the other side of like almost being too slim” (‘Susan’)

“I think that pretty much her words were, because you’re not a a an imminent danger to yourself, even though I would recommend some sort of counselling, which you can get on the NHS, you’re gonna fall very far down the list.” (‘Emily’)

4.3.5.4 Positivity

There was a lot of positivity coming from individuals who were in the process of recovery or felt that they had recovered. It is important, as part of the analysis of self, to include this theme, to reflect the experience of the recovery process, the hard work and the progress that is possible with EDs/DE.

“I’m in recovery n I feel quite confident that I’m gonna I’m gonna do ok, I feel more I just don’t want it to happen to to anyone, I wouldn’t wish upon anybody it’s it’s the most horrible thing nd I I think that ye just I actually am happy to talk, that’s why I wanted to do this interview with you I’m actually like I want people to know. I just think it’s that’s how it can be stopped earlier nd just it’s not something, people are actually properly poorly! N they actually need help it’s not just it it’s not just something they can get over.” (‘Amber’)

“I’ve always tried to tackle it myself, um, I am currently, however, um, now managing to tackle it and have probably, and feel more positive, more secure in tackling it than I have done in, ever, er, time” (‘Grace’)

“I’m proud of who I am now and um I wouldn’t change anything, even the bad things of what I’ve been through, I wouldn’t change them for the world. Because I’m not ashamed of them.” (‘Kelly’)

“I think that it’s changed, that I’ve changed. I’ve now got strength that I didn’t have before because I don’t have it any more. I’ve got strength because I’ve given it up.” (‘Ashleigh’)

4.3.6 Improvements

Four themes were identified within this section of the interviews: Perceptions of EDs/DE; education; training HCPs around weight and DE; improving access to services.

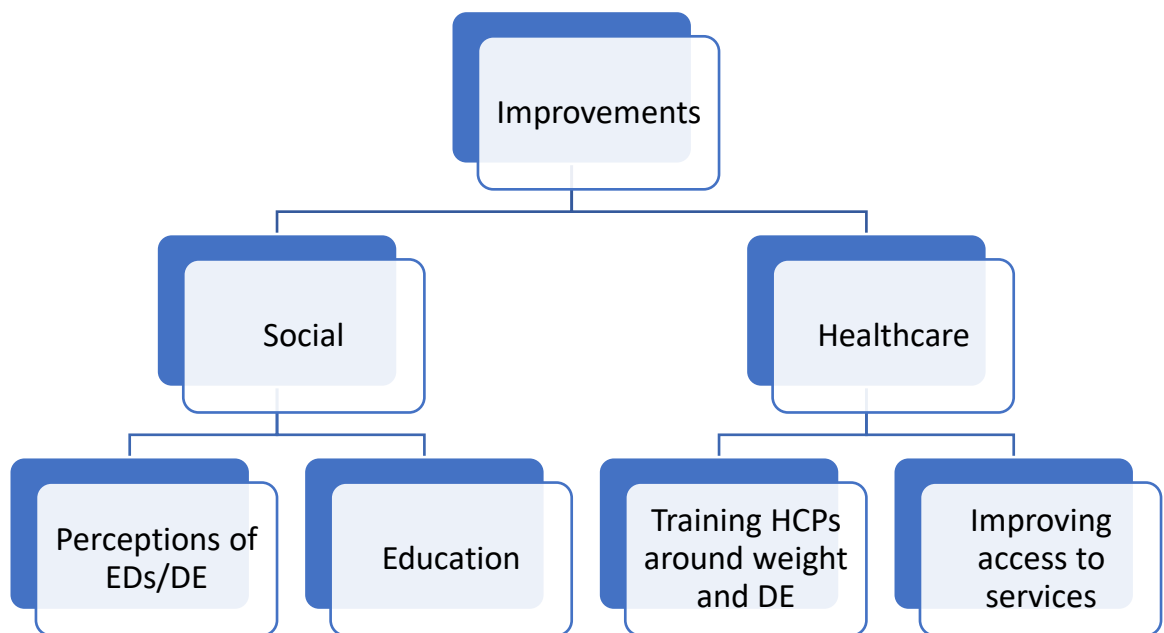


Figure 7: Thematic map of suggested improvements

4.3.6.1 Perceptions of DE/ED

Participants expressed a lot of concern over the media presentation of EDs and DE as well as concern around the assumptions that they felt were routinely made. These presentations and assumptions were seen as an active barrier to making improvements and as such is included in this section of the analysis.

“It’s very misunderstood. I think that everyone just assumes when you say the word eating disorder that you’re trying to be skinny but actually you’re just trying to get rid of all of the demons in your head” (‘Ashleigh’)

“An eating disorder isn’t the one picture that people have of it. You can be just as sick at a different at a healthy weight or overweight as you can be underweight and you shouldn’t get help just when certain behaviours kick in. You should receive treatment for any disordered behaviour.” (‘Eve’)

“We need to stop seeing the danger in it just when people are thin. Like we need to start realising that like this is so dangerous” (‘Naomi’)

“We need to stop using super skinny images and saying this is, this is what anorexia looks like because it’s not. You know that is a very a very severe representation and I mean there’s a lot of people, like me who might still be underweight but not glaringly obviously thin um who are then kind of thinking well I don’t have a problem I don’t deserve help I shouldn’t get it you know an then there’s people who are a healthy weight or overweight or whatever who don’t think that they deserve help either. It’s just ridiculous. I mean it always seems to be a teenage white girl. Always.” (‘Natalia’)

4.3.6.2 Education

There was an acknowledgement that there was a general lack of awareness about mental health across the board. From this there were suggestions around improving education in schools around mental health and self-care in general although there was some caution around the potential to trigger people

There were also suggestions around making the school environment in general a more mental health friendly place, increasing teacher awareness of potential signs and symptoms, as well as suggestions to provide space for individuals to be able to form trusting relationships that would enable them to talk about things that were troubling them.

“If I had known at like 14, 15 that I should not be hating my body but I should be loving it and the, you know, if I do the right, if I look after myself then I can live like a great life, I could’ve prevented ten years of hell. And I think having a go-to person at school, if they have a worry even” (‘Naomi’)

“It needs to start at school though. It’s about coping with life” (‘Grace’)

“I think the teachers need more training and awareness um you know they need to understand a bit more about it um some of the you know the little things that maybe they could do to help” (‘Natalia’)

“In schools especially it’s too, to have things in place where people really feel that they can go and speak to somebody ... I think it’s about inviting them in to, ‘do you wanna just come an have a chat for five minutes?’ They may be the normalist person in class but just say do you wanna come in an have a chat an so they just get the opportunity to come in and say, an just say ‘how is your day?’ ... just building a trust. I think if someone went to see someone every week for five minutes five or ten minutes that would have a huge effect because then eventually they might say something, that they go, actually this one person seems to actually care about me. I’m going to, I wanna tell them something. I can tell this person” (‘Ashleigh’)

4.3.6.3 Training HCPs around weight and disordered eating

Weight was seen as a barrier to HCPs understanding what the individual was struggling with, with individuals at a higher weight being reluctant to see the GP with their DE for

fear of not being taken seriously, individuals attending GP surgeries to have their issues accepted but told that they won't get access to services because their weight is not low enough, and individuals explaining their DE to GPs and being told they must be weighed. There was a lot of strong feeling that where HCPs were using weight as a criteria for access to treatment they were missing the point of what it was to have DE/ED.

"I don't think they should use BMI as an indicator of like an eating disorder you know coz it does affect people at all weights coz you know you can be a healthy weight an still be struggling with exactly the same thoughts as someone that's in an inpatient unit. Um so you know the use of BMI it doesn't really tell you that much. Well I suppose it is useful as an assessment tool for physical risk but ultimately eating disorders are a mental health problem" ('Natalia')

"I think it was just difficult because for like for quite a long period of time like the time that my eating disorder was worse it wasn't when I wasn't eating – I was quite happy and I just wasn't eating it was quite simple, but a definite a definite period of time where I'd try and restrict and I'd eat like a cracker and then throw it up ... that was when I kinda realised that I was at a low point but like my weight wasn't really like my weight wasn't really dropping because I was eating and throwing it up and eating and throwing it up and like to the GP that's like a period of time where everything is fine because my weight is stable when actually like my health was a lot worse than when I wasn't eating" ('Lucy')

"They would belittle the problems because my weight wasn't, perhaps a suggestion that it was a huge issue. And if you, the DSM for instance, anorexia can only be diagnosed if someone is underweight. It's just, someone who's kind of the same weight, doesn't vary that much is pretty is normal weight probably is not a priority for anyone" ('Joanne')

There was a lot of understanding of the pressure on GPs however, this was seen as something that could and should be addressed in order to treat DE and EDs when they present.

4.3.6.4 Improving access to services

There were many stories of waiting – waiting for assessment, for treatment, to be transferred from one service to another. Immediacy of access was cited as important as waiting tended to exacerbate the issues allowing the behaviours to become more engrained.

"But for me I think that also when you're seeking that help, it's the most important thing, for me, is that is done so quickly." ('Ashleigh')

"With regards mental health it's very hit an miss whether they'll make referrals or treat you with respect or coz obviously I've seen both sides of the coin. I've been treated with respect and I've been treated with, you know, total lack of respect so I've kind of seen both sides to it really um so yeah just more consistency I think in

how they deal with things an I know there is a lot of inconsistency around the country with regards to mental health. Sometimes it's a postcode lottery as to what treatments you get." ('Zoe')

"I'm pessimistic because I don't think much can change until the NHS creates new places and, but I think those two things are really important: 1. not regulating the private sector and 2. Ensuring that if our patient care has to be in the private sector the people providing care are regulated and have to follow NICE recommended care processes or whatever." ('Joanne') <followed a discussion on the lack of regulation in the private sector and the problems around this>

"I do think that there should be more help there like in schools an think the doctors should do a bit more before it gets any worse coz it's like a disease. It does spread. The quicker it gets sorted the quicker the person'll heal whereas if ya go fa years sufferin an a longer time recoverin an I do feel that they should try an help before it takes over an ruins their life or I think er one a ma friends committed suicide because of it. I do think they should try, before it does get worse." ('Teresa')

There were no distinctions to be made across the weight categories for this aspect of the analysis. The participants spoke 'with one voice' about the damaging assumptions around, and portrayals of, EDs, improvements that could be made across the healthcare and educational settings – there were very few examples of smooth progress through services but those who had had good treatment also raised the same issues.

5 Discussion

From a critical realist ontological position and taking a contextualist epistemological stance, this research sought to explore the experiences of women across the weight spectrum, who have lived with/experienced DE, to determine their perceptions of how weight has influenced their treatment in these contexts, and to gain insight into how weight may be influencing views and responses to DE. The concept of EDs tends to bring with it preconceived ideas about weight presentation, although EDs/DE can occur at any weight. Using a 'weight-blind' approach to the data, themes and shared experiences were identified, across the weight spectrum, within the different contexts. Although some aspects were particular to certain weight presentations, there was an overall picture across the variety of experiences. The following sections provide a summary of the general contexts and how weight impacts in these areas.

5.1 Family

'Genetic inheritance' is a concept that is sometimes used/misused as a frame for understanding health issues and from a health psychology perspective it is important to acknowledge such influences. There is evidence to support a role for genetics in terms of child weight (i.e. Durmus et al., 2012), AN (Brandys et al., 2015) and DE in general (Wade et al., 2013). However, the psychological and social aspects of the family are key. Within this research, the family context revealed how central the family is in terms of the development, recognition and recovery from DE. Across the various models (section 2.4), the importance of the family environment is stressed, however, this is a sensitive and complex subject. Participants showed understanding and sensitivity around this issue: there was a desire not to 'cast blame' in general terms; 'intent' was not evidenced (in most instances) and as such the concept of 'blame' is inappropriate (le Grange et al., 2010). There were a number of cases though where participants understood that the difficult relationships in their family had played a key causal role.

This relates to the literature regarding Adverse Childhood Experiences (ACE) and there is clear evidence of the impact of ACE in regards to mental health in general (Kessler et al., 2010; Moore et al., 2015; Fergusson et al., 2008). There is also evidence to suggest that ACE is significant in terms of EDs: emotion dysregulation in parents has been associated with the development of DE in adolescents (Hansson et al., 2017) and family conflict in general has been linked to 'risky dieting' (Hinchliff et al., 2016) and weight-loss attitudes

via psychological distress (Thomas et al., 2017). Castellini et al. (2018) found a subpopulation of participants (in their study of EDs) who were less responsive to treatment, more likely to have complex comorbidities and also more likely to drop out of treatment; this subpopulation had higher levels of ACE. The recommendations from such research focus on the need to establish where such histories/issues exist in order to construct an appropriately tailored treatment approach, taking into account the additional impacts of ACE, and on the need for support for families around improving relationships and positive parenting. However, this strays into the realms of criticism and blame. As le Grange et al. (2010) suggest, moves should be in the direction of supporting sufferers and easing family burdens with decisions on how to achieve this being made on a family to family basis.

In line with this, Jorm & Mulder (2018) suggest, along with improvements to treatments (in access terms too), more focus on prevention, suggesting five specific areas they feel may lead to benefits in the longer term regarding mental health rates and outcomes (better economic support for families; changing social norms to better support parents and positive parenting; better quality care and education in early childhood; enhancement of parenting skills to promote healthy child development; and intervention to lessen harms and lower future risk). This relates to the current research as, for many participants, the framework and/or 'safe space' they desired within the family were not present and individuals whose families benefitted from input from ED services indicate that constructive engagement, provision of knowledge, new skills and understanding, was helpful to the individual recovering from an ED.

The causal impact of role-models and structure around meals was clearly evident, being understood by many as 'setting the stage' for DE and this idea does have evidential support. There is a link between parental behaviour, weight/dieting and the development of disordered eating: Neumark-Sztainer et al. (2010) found that there were particular issues when 'weight-talk' came from the mother ("unintentional harmful consequences", p270); these findings are echoed by Kluck (2010) and also Arroyo et al. (2017) regarding 'intergenerational transmission of DE'. Further, and in addition to the links between frequency of family meals (Neumark-Sztainer et al., 2008) and parental style (Fiese & Bost, 2016 – see section 2.1.1), we can look to developmental theory to provide some additional insight, considering that the majority of individuals cited their early teens as a time when DE originated. Piaget's Formal Operational Stage begins around the age of 11, the point at which abstract thinking commences and the individual becomes capable of

higher-order reasoning. This would enable the child to think about their weight, activity levels and diet independently of the parents/caregivers. It is also a point where, with the shift to secondary schools, there is less monitoring of behaviours around food by both parents and school. Erikson's stages add to the argument for adolescence being a 'pivot point'; early adolescence is the point of 'identity formation', the epigenesis of the individual. Building on the identifications they had with key caregivers, the adolescent creates their own identity (sometimes taking the form of a 'negative identity', almost in opposition to their caregivers' identities). Essentially then, this is the point where the child's independence commences. This creation of identity is dependent on social response however, so depending on individual situation, one can envisage cases where childhood patterns are continued as well as cases where they are not and, as with all change, there is the potential for the transition to be less than smooth (Slotter & Walsh, 2017).

With regard to the construction of identity, there would also appear to be a link from these aspects of the family to the self-schema model (Stein, 1996), whereby the family provides the declarative schemas from role-models (how to be/ideas about self) and the procedural schemas from the structure/routines around food (what to do/behaviours). Where the structures/routines were not put in place by parents this was cited as an issue for many participants. Stein and Nyquist (2001) suggested that the focus of therapy should be on the creation of new positive self-schemas rather than on weight and food as the latter can serve to exacerbate. Various participants had felt that there was too much focus on the physical aspects of their DE (i.e. weight restoration or weight reduction, also identified by Bannatyne & Stapleton, 2016). It was also notable that several participants cited finding an interest and value in something other than their weight/bodies as fundamentally important to the process of recovery. Certainly, where physical health risks are present there is a need for input in this respect, however, being able to provide a sense of meaning beyond that may be important for sustained recovery: a move away from a focus on weight may well be fundamental. For the individuals with good familial relations, the disruption of schemas could be seen to have occurred through different triggers (i.e. pressures at school, bereavements, etc.), which ties in well with Stein's model.

5.1.1 Weight and family

That the only families who took direct action to address ED/DE behaviours were those where individuals became a very low weight/physically frail suggests a weight-based perception that low weight equates with ill-health and a need for support/treatment. Several participants presenting at higher weights had their weight targeted by their families, either through direct control of food intake, encouraging attendance at commercial weight-loss clubs or through criticisms. There were comments from participants on the assumptions made around being at a higher weight (i.e. no assumption of underlying issues with DE or an ED) and that gaining weight equated to being happy. Losing weight, from a starting point of a higher weight was also received positively by peers and family in most instances; again, no assumption of underlying issues with DE/ED. The assumptions based on weight within the family appear to represent commonly held misunderstandings around weight and health.

5.1.2 Family – summary and improvements

This context is highly sensitive, controversial even, requiring due consideration and an approach that avoids ‘blame’ and promotes contextualised co-operative working. Acknowledging the importance of role models and structure, of the impact of ACE, and the potential issues associated with the stage of development at which the majority of individuals identify DE origins, improved awareness and education would appear to be a logical suggestion and this was observed in the suggestions made by participants as well as researchers.

There was recognition around the sensitivity of this context but participants were also keen to point out that, where the family environment is unhelpful or even ‘toxic’ to the individual, that getting away from that environment will be fundamental to recovery. Individuals who had come through Child and Adolescent Mental Health Services (CAMHS) and not had access to one-to-one appointments without the presence of a parent, felt that this had been unhelpful in terms of building trust and enabling them to be open about their circumstances. Participants whose families had been open to and had received input from healthcare regarding how to support them etc., reported benefitting from this however, there were instances where this had not worked well and the parents had felt blamed and then distanced themselves.

More education around positive parenting was also put forward by some participants, and this links in with Jorm & Mulder's (2018) recommendations for preventative strategies.

5.2 Healthcare

The healthcare context was difficult for many participants. There were issues around approaching a HCP in the first instance, issues with HCPs re-framing or not recognising/acknowledging issues, and issues around a lack of understanding from HCPs. The first two issues could be related to the perceived power imbalance between HCP and patient, relating well to Palmer's (2014) discussion of 'filters' in terms of accessing treatment. Initial filters concern the individual, their recognition of an issue and then the step to take it to the HCP (section 4.2.2.1). With the HCP there are further filters regarding recognition and Palmer refers to the "... arbitrary nature of many of these defining boundaries..." in terms of diagnosis (section 4.2.2.2). Issues with diagnosis (section 2.2.4) hold significance in terms of EDs/DE and raise an important question in terms of service provision around intervention – should we wait till an issue has reached 'clinical significance' diagnostically or should we act more preventatively?

Knowledge and assessment of DE is also of issue though. Newell (2010) discusses the issues around identifying EDs in primary care. That EDs are relatively rare, he notes, is a reason why some HCPs have little to no experience, or have incorrect beliefs (i.e. around gender or race). This was notable in the participants' narratives where HCPs did not appear to recognise the condition or the seriousness of it. The issues around secrecy and denial (EDs being acknowledged as ego-syntonic) also make it harder to have an open dialogue within the consult. To address this, as well as the possible power imbalance, Oakley et al. (2017) single out the role of the nurse as holding potential for identifying EDs, due to the less formal nature of the consult allowing for more disclosure. They also suggest that the SCOFF questionnaire can act as a useful (and brief) tool for assisting with this.

Although there is an attempt to move healthcare decisions in the direction of co-production/co-creation (Crimlisk, 2017; Chambers et al., 2017; Batalden et al., 2016), the reality is that making the move means overcoming some barriers and misunderstandings. The drive towards including the patient more actively in decisions around their healthcare has been steered by the 'No decision about me without me' consultation and accompanying mandate which: "... sets out a clear ambition that the NHS should become

dramatically better at involving patients and their carers, and empower them to manage and make decisions about their own care and treatment.” (DoH, 2012) which necessitates a recognition of the expertise of the patient regarding their own experience and preference. This, however, runs contrary to an arguably embedded perception of HCP as the ‘holder of the knowledge’ and the patient as passive receiver/compliant patient. As Koeck (2014) explains: “Patients yield up power to physicians because one has knowledge and the other is apparently ignorant. Doctors decide and patients follow. Consequently, the patient-doctor interaction is unbalanced, encounters are short, and communication is replaced by diagnostic intervention. The information patients could provide is ignored, devalued, and not used in the search for treatments appropriate to that patient.” This imbalance impacts negatively on both practitioner and patient, with the HCP bearing a heavy weight of responsibility that leads to “...isolation, exhaustion and unbearable fears of failure.” (p1).

This imbalance was evident in many of the narratives from participants whose distress was re-framed as something other than DE/ED or where patients were told their distress/issues were not significant enough to warrant treatment. A further disturbing factor cited by Newell (2010) is attitudes that EDs are ‘self-inflicted’ and, thus, less deserving of treatment. Participants spoke about feeling they did not deserve treatment, partly because they themselves felt they were not ‘ill enough’ but also in conjunction with the lack of recognition from the GP (not being ill enough for the GP to notice). Clearly this acts as a barrier to accessing effective treatment. Add to this instances where participants were informed their BMI or weight was not low enough to warrant treatment, this ignores the psychological distress of EDs, and delays treatment: treatment before patients become ‘severely underweight’ is recommended (e.g. Deering, 2001) as is early intervention to prevent further entrenchment of behaviours (Schmidt et al., 2016; Brown et al., 2016). This research suggests that, in the majority of instances, early intervention is not being facilitated, either through a lack of understanding/recognition from the HCP ‘gate-keeper’ or through a lack of services. It also suggests that the move to co-production and including the patient’s own expertise is not being enacted. Joseph-Williams et al. (2014) suggest that there are engrained attitudinal barriers that still need to be addressed as this does represent a significant behavioural change on both sides of the consult. They also point out the structural and process issues (i.e. time spent with patients leading to the use of “fallible heuristics” (Kreuter et al., 1997)) and “white coat

silence” (the tendency for patients to not ask questions/be intimidated by HCPs, Judson et al., 2013).

5.2.1 Weight and healthcare

Weight featured in the responses from HCPs reported by many participants (section 4.2.2.4). In GP surgeries, in hospitals, and with interactions with nurses, participants reported responses that appeared to be based on weight and appearance and assumptions that EDs/DE are about weight (“*why else would you do it?*” (‘Ashleigh’), section 4.2.2.2). The appearance of being able to function was also seen by some as a barrier to being acknowledged or receiving treatment - the priority was perceived as being given to the ‘visibly vulnerable’. This provided many with the message that unless they were underweight, their distress did not warrant support or treatment. Some people, in response to this, sought private treatment and felt they had benefitted from this - the treatment enabled them to reduce their distress, reduce the DE behaviours, and improve their standard of health and wellbeing.

Service availability was an issue. Participants cited examples of being told that their BMI was ‘too high’ for them to get access to treatment which gives a clear message that EDs get noticed when you are underweight only. Considering the rates of the various EDs (Beat, 2015), this would mean that less than 10% of people with an ED would get treatment (as not all individuals with AN present at a very low weight).

5.2.2 Healthcare improvements

Along with an increase in service provision, service-access criteria/methods would require revision (taking into account the issues with diagnosis as well as the need to act preventatively and early), more training regarding EDs/DE and an attitudinal shift. The referral process can be time-consuming (although in some areas, in terms of mental health, rapid responses can be requested) and there is a risk of not being accepted into a service. BMI ‘barriers’ led to prolonged distress, more time using DE behaviours, DE behaviours becoming more engrained, more time where quality of life and health were being negatively impacted. Beat (2017) have stressed the importance of reducing delays in accessing treatment and this was echoed by the participants.

5.2.2.1 Listening

The experience of not being listened to and not having DE behaviours acknowledged as being serious was also a clear outcome from this research. EDs are strongly connected visually with the image of being very underweight and this was something that participants wanted to be raised - the danger in DE does not only exist for individuals in that condition but for all individuals with DE. Although the RCGP (2017) refuted the suggestion that there was a fundamental misunderstanding of EDs, the evidence suggests a different picture. There was a strong recommendation from participants that GPs and HCPs get up-to-date training on EDs and DE in order to better respond to individuals seeking help.

5.2.2.2 The position of the GP

Participants did speak of the difficult position of the GP and, in today's healthcare environment in the UK, this has been acknowledged. The expectations on a GP consult have increased, with patients' weight being something that they are asked to raise more frequently. This has led some GPs to bring weight into a consult where it is not appropriate (one participant was weighed during a consult about tonsillitis despite already being with an ED service where she was regularly weighed and was subsequently advised to lose weight). The responsibility on GPs is higher than it has ever been and we see this reflected in the 'recruitment crisis' (Jones, 2017). Levels of GP burnout are high and there is no system in place for GPs to flag their distress, as there are in other high-pressure jobs (O'Dowd, 2015). Although some suggest particular practices can be used to help reduce this stress (Thakur, 2015) and that the education process can do more to help trainees develop the resilience they need (Sales et al., 2016), more specific training in EDs and DE were suggested by participants and also by Beat (2017). In addition, further guidance around moving towards co-production and working with the patient in order to achieve the mandate to the NHS (DoH, 2012) would assist in moving towards a shared holding of responsibility which could benefit GPs. The attitudinal shift needs to occur on both sides of the consult however, and there is more to be done if we are to achieve this change in perceptions of healthcare (Judson, et al., 2013; Joseph-Williams et al., 2014; Koeck, 2014) much of which needs to be led by those in the current 'power' position, i.e. the GP/HCPs.

5.2.2.3 Triage

There was also a suggestion to improve the triage abilities of GP surgeries by situating psychologists within practices to assist with the triage process. There are currently pilots whereby mental health professionals are embedded within GP surgeries to assist GPs in terms of the need for referrals, to act as an essential sign-posting service, and providing rapid contact with mental health services. It is too early to draw any conclusions around the benefits to patients of such pilots however, early indications suggest that this is simultaneously helpful to GPs and mental health services in terms of improved patient management (personal communications).

5.2.2.4 A re-focus on health

Some participants suggested a 're-focus' whereby GPs guided people in terms of healthy diet, healthy balance, rather than place emphasis on BMI and the appearance of health. Instead of weighing an individual in a consult, asking routine questions around nutrition and activity, regardless of the weight presentation of the patient, may lead to a more appropriate message around actual health-improving and health-maintaining behaviours. This would require a shift in the guidance, away from the current diet-culture. The promotion of such approaches within the NICE guidelines (2014) is especially problematic in light of some of the experiences from participants who referred to commercial slimming clubs as fuelling ED thoughts and behaviours through their systems of rules and using social pressure with the group and the connections, a link that has also been noted in the research around public health messages (Austen, 1999; Hesse-Biber et al., 2006). Notably, the tiered system in Wales for weight management (Welsh Government, 2016) does not use such clubs, placing psychological support much earlier on in the tiers in recognition of the difficulty around health behaviour change which raises an interesting question around why this remains part of the NICE guidelines in the UK: while the rules and restrictive practices of diets are seen as 'normal' and an effective way of managing weight, it is natural that individuals will continue to follow this path in search of a 'healthy weight'.

5.3 Social

The social context did not appear as a strong theme in terms of influencing individuals around weight although it did play a key role for some individuals. How EDs and DE is represented in the media WAS seen as problematic as it served to fuel an unrealistic

image (mainly the extremely underweight young female). That EDs/DE can affect anybody was a clear message from participants, and they wanted this to be made clearer. The role of social media in terms of promoting body positivity was seen in a positive light however, the 'dark side' of social media provided the counterpoint to this.

5.3.1 Social formal

The Foresight report (2007) lists a variety of environmental factors that influence weight and the issue of the broader situation for the patient with ED is also detailed as important within the NICE guidelines (NG69, 2017) and, as part of a biopsychosocial perspective, the environmental factors are an important part of health. As social beings, we are influenced by the places and the people we spend time with and these aspects featured strongly in the suggested improvements from participants.

5.3.1.1 The school environment

The age-range of the participants represented a period of significant change in terms of pastoral care in schools with some participants noting improvements apparent in the schools they had left just a few years previously. This is an area that continues to receive attention, partly because adolescence is a time where mental health challenges can increase but also due to a recognition of the significance of relationships at school. There is more of an expectation on schools now that they will educate about health and wellbeing through PSHE classes (personal, social and health education) but also that they will provide space and opportunity for students to talk if the need arises. With a special on 'mental health and wellbeing of children and young people' scheduled for this year in the journal *Pastoral Care in Education*, this is clearly an important topic. There is a distinction to be made between the primary and secondary school systems in terms of the emphasis: Willis et al. (2012) found that the 'personal wellbeing' aspect was seen as less effective in secondary schools than primaries (and the reverse in terms of 'economic wellbeing') however, considering the significant changes during adolescence, more emphasis is required on personal wellbeing across the entire school experience. Maelen et al. (2018) suggest that an emphasis on the whole person (pupil-centred educational practices) was more mental-health friendly, whereby the teacher-pupil interactions went beyond that of the purely academic, to build a more trusting and nurturing relationship. When pupils feel more comfortable speaking to adults they are more likely TO speak to adults. However, the

school context itself is seen as important. There is a drive from organisations such as The CoEd Foundation to promote compassion within schools by weaving it through the curriculum, everyday practices and behaviours (e.g. Coles, 2015, 'golden thread' of compassion), the hope being to create a more supportive and nurturing environment, better suited to the task of preparing young people for life and promoting mental and physical health and wellbeing.

The NICE guidance (PH20, 2009) recommends that social and emotional wellbeing be promoted through schools as one part of a multi-agency strategy – liaison with parents, CAMHS and other services is crucial. Clearly, for some participants, such liaison did not occur. Further training in terms of recognising early signs of potential issues such as DE would further support teachers to fulfil this role and Finney (2008) calls for training for educators in mental health competencies for this reason.

5.3.1.2 The work environment

Work practices were identified as impacting on health behaviours, specifically eating behaviours, by some participants and this is reflected in recent research by Winkler et al. (2018). They found that 'non-standard work schedules' (NSWS) impacted negatively across a variety of health behaviours including dietary practices. The importance of the work place in enabling individuals to routinely engage in health-promoting/maintaining behaviours is perhaps more important in the current climate where NSWS are increasingly common.

The impact of military service came up in the data. Although there is a lack of research regarding the influence of military life on eating habits, there is evidence of 'socialisation to poor eating habits' (Breland et al., 2017), including an expectation to eat large amounts of food quickly (encouraging binge-like behaviours) and irregular eating schedules. Participants that spoke of personal experience within the military talked about the expectation to 'eat every meal as if it were your last' when on active duty. There were additional factors around stress and military-based trauma which were seen to impact further on their eating behaviours. Previous studies have also linked post-service BMI to the impact of military service partly through the food environment and food insecurity but also through the additional stressors of military service. The picture here is likely to be highly complex but what we know already links closely to participants narratives.

The Health Foundation (2018) suggest that, in a post-Brexit Britain, there is the opportunity to re-examine how health is situated in policy terms, suggesting a 'health-in-all-policies' approach ("... an approach to public policies across sectors that systematically takes into account the health implications of decisions, seeks synergies, and avoids harmful health impacts in order to improve the health of the population and health equity." p3). They suggest this approach "...could put centre stage the protection and promotion of the publics' health." (p3). With the need to have UK legislature in place, this provides an opportunity to bring the health impacts of workplaces, farming, education etc. to the fore; an opportunity which, if the participants of this study are to be responded to, should be actioned.

5.3.2 Social-informal themes

Derenne & Beresin (2018), in an update on 'body-image, media and eating disorders' found that rates of EDs remained constant despite the rise of social media. The positive influences (i.e. the rise of the body positivity movement) appear to balance the negatives in terms of media influence however they encourage modelling of healthy use of media by adults. This balance was noted by a number of participants.

The 'thin-ideal' was not explicitly present in the majority of the participants narratives however, the need to be in a smaller body was apparent from participants who had experience of living with obesity or in a larger body. The narratives in society around what was 'healthy' as well as narratives of recovery were noted by some as well as the promotion of the 'vision' of health.

Direct comparison with peers was not mentioned. This has been evidenced in other research supporting the socio-cultural model (Halliwel & Harvey, 2006; Vander Wal et al., 2008) so its absence is of note. Certainly, appearance played a role in terms of judgements of being deserving of treatment as well as judgements from HCPs regarding health status.

It is possible that the more recent changes in fashion marketing, with a variety of body shapes more increasingly being used as mannequins in stores and a greater variety of fashion clothing available at a wider range of sizes, as well as the rise of the body positivity movement and organisations such as Health At Every Size and Endangered Bodies, is having an impact on socially conveyed messages around body size. This may represent the beginnings of a cultural shift which would impact on socio-cultural influences, but this would require further exploration and data.

5.4 Self

Recovery from ED/DE is not as well defined as one would expect, with many outcomes only measuring change in pathology or remission. In a recent meta-analysis, de Vos et al. (2017) noted that individuals rated psychological well-being as central to recovery, including aspects such as self-acceptance, resilience, adaptability, positive relationships and personal growth. Certainly, among the participants who felt a degree of confidence in their recovered status, there were expressions of knowing how to handle the stresses of life better now (resilience), how to spot the signs of pressure increasing (adaptability), and, crucially, had felt personal growth and a sense of meaning which over-shadowed the feelings of control their ED had previously given them. This research does not aim to evaluate 'recovery status' and the research around identity and health is vast, however, these narratives were notable. Equally, there were individuals who felt they were 'stuck' and unable to understand their behaviours currently - their DE was still controlling and offering a sense of being in control and a means of coping with life.

5.5 Links to the literature

5.5.1 Food and identity

The complex role and meaning of food and food-related behaviours was apparent in the themes. Food as a means of identity (i.e. Ogden, 2010) was evident in participants' narratives: there was a 'losing of self' that linked with food behaviours being hidden, social settings for food being avoided, and a confusion around identity for many, with the DE often seen as 'taking over' their identity. This was not exclusively linked to those with an ED diagnosis, suggesting that this is not 'simply' explained through the lens of mental health, and points to the importance of food in the performance and understanding of identity; the importance of supportive people 'staying connected with me' further highlights the importance of identity in terms of recovery. Parsons (2015) suggesting that food-behaviours are 'affective practices', enacting embodied demonstrations of identity appears in the participants' experiences as the distress and pain of both their food-related behaviours, the impact these had on their bodies and the assumptions and judgements made about them on the basis of their weight presentation.

In a society where food is now abundant, does this contribute to individuals' struggles to perform/demonstrate or even understand their own identities? With the numbers of individuals struggling with food and weight related issues and the current consumer

culture, it is possible that a ‘distortion’ of the hidden meanings of food may be at least a contributory factor, especially in terms of the distress of DE.

5.5.2 The role of the family

The role of the family in transmitting norms around food was also clearly evident. Participants highlighted the impact of parental food-related behaviours, routine and extreme dieting as a norm and a lack of structure to mealtimes as ‘setting the scene’ for DE, which links strongly to the work of Neumark-Sztainer et al. (2008) and Fiese & Bost (2016). Similarly, participants whose parents had been openly displayed dislike of their own bodies were seen as influential role models in terms of their own relationship with their body image – the concept of intergenerational transmission of such ideas has received support within the literature (i.e. Arroyo et al., 2017; Neumark-Sztainer et al., 2008).

5.5.3 Visual indicators and the medical consult

The experiences of exchanges with HCPs revealed evidence of visual indicators being used (weight, appearance, functionality/coping) to determine both the severity of the DE as well as access to treatment, with patients at higher weights being deemed a lower priority for treatment – Foucault’s ‘active eye and mute body’ apparent across these exchanges and running contrary to the desire to involve the patient more in their own healthcare. With notable responses from HCPs including “You look ok to me” and “She looks great”, as well as “we need to weigh you” (to determine whether an individual with BN had an ED), a move beyond weight and the visual is clearly needed if DE is to be recognised. That an individual appears to be functioning well does not discount the possibility that they have an active ED – and those DE behaviours will have an impact on that individual’s health. The power of the medical consult (i.e. Zola, 1972) also impacted individuals, in many cases (although not in all) resulting in a worsening of DE behaviours and a decline in health, a lack of validation and acknowledgement from HCPs prompting many to question whether their distress and DE was ‘serious enough’ or, in fact, a problem at all.

5.5.4 Weight and identification of DE

With DE behaviours indistinguishable from many standard dieting behaviours (e.g. extreme restriction, skipping meals) there is great potential for confusion around what IS

and what IS NOT healthy. The noted risks of DE behaviours in terms of general health and weight gain as well as the lack of detection of DE among adolescents classified as overweight or obese (e.g. Nagata et al., 2018, evidence of which was observed in the current research data) indicate that we should be placing a much greater emphasis on the food-related behaviours and discouraging many currently accepted dieting behaviours.

5.5.5 Stigma – the assumption of control

Considering the current pressure on health services within the UK it is difficult to determine what was influencing the different responses experienced by participants at different weight presentations. There is strong evidence that services across the country vary (i.e. Beat, 2015; PHE, 2015, RCP, 2013, National Obesity Forum, 2014) and that services may be ‘rationed’ in these circumstances. However, there were clear examples of services not being provided on the basis of weight, as well as DE not being recognised on the basis of weight. Some participants spoke about direct, verbal abuse in the social context due to higher weights, and others spoke about not being taken seriously because their weight was deemed ‘too high’ to be problematic, or the suggestion that they had control over their weight (i.e. Puhl & Heuer, 2009; Reas, 2017). Others experienced expressions from HCPs suggesting that they should be able to ‘just get over’ their eating issues on their own, indicating a belief in personal responsibility and control over their DE (i.e. Roehrig & McLean, 2009; Puhl & Suh, 2015). These can be taken as at least suggestion of stigma enacted across the social and healthcare contexts, the assumption that the patient has free choice regarding their behaviour – an assumption that is far removed from the reality of DE.

5.6 Implications for theory

5.6.1 Models of Eating Disorders

The self-schema model of EDs was most strongly supported by the current research, i.e. the emphasis within the causal narrative on early experience and the idea that finding meaning and value beyond self/body is important to recovery. Further support for this model comes from the part that role-models and routines play in ‘setting the scene’ (formation of schemas): individuals whose parents were dissatisfied or critical of their weight and appearance (declarative schemas) identified these experiences as significant and where participants had experienced a lack of structure, they had found it

simultaneously easier to engage in DE practices (i.e. greater opportunities) as well as to find those practices 'normal' (until self-identified 'turning points'). The 'behaviour trap' particularly relates to these procedural schemas as does the difficulty in changing engrained habit. The more recent findings relating enforced dietary rules (e.g. type 1 diabetes and coeliac) to DE behaviours adds strength to this suggestion (Latzner et al., 2018).

The strong narrative around identity in the data adds power to the suggestion that an individual's identity is significant in terms of behaviour change (Kearney & O'Sullivan, 2003). This is not a new concept regarding EDs (e.g. Bruch, 1979) but one that may require a fresh look. With patients perceiving treatments for EDs as punitive and blaming and focussed on the physical aspects, a re-focus on self and identity may be the path to take to improve treatments.

Regarding the cognitive interpersonal model, obsessional thinking was something that did occur in each weight category, suggesting that the cognitive predisposing traits may have a role to play in a range of EDs. The 'numbing' that is suggested to occur within this model was apparent across the weight spectrum also, broadening the applicability of this model to EDs other than anorexia.

The lack of support for the socio-cultural model in this research does not imply that there is no role for comparison; the social pressure to present oneself as a 'responsible citizen' (Parsons, 2015) was present, if indirect or implicit, in the way individuals were perceived and responded to. Social expectations seemed to place pressure on individuals to appear to be healthy and appear to function ('responsible citizenship') and if they achieved those things they were not seen to be needing help, even when they asked for it. When an individual brought themselves into the 'healthy' weight range rapidly from a higher weight, they were congratulated rather than questioned, on either the approach they took or whether they were, in fact, ok. This raises questions not only around the assumptions being made, but also on what mechanisms are keeping these assumptions active.

5.6.2 Models of ED – summary

There is immense complexity and a tendency towards diagnostic migration within ED diagnoses. The concept of mental health diagnosis itself brings with it significant questions around biological reductionism and the stripping of context. There is not one path to DE/EDs – the aetiologies are multi-factorial and provide an originating context. If

we are to provide a model from which to work, the data from the current research would suggest that a model able to bring together and acknowledge the various contexts and place identity at its core may prove more fruitful; reliance on weight as a signifying feature for DE, as evidenced in the current research, will continue to leave many individuals experiencing the distress of DE, mentally and physically, without support or treatment.

5.6.3 Models of obesity

Turning to models of obesity we can see a significant degree of overlap. The social-ecological theory, with its systems theory approach, applies to DE as much as it does purely to weight, with multiple factors impacting on the individual including personal, familial and wider societal factors. Complex, multi-factorial aetiologies are the rule where no single factor may be isolated as 'to blame'.

Neuropsychological factors around the concept of 'addiction' lack sufficient evidence currently (DSM-V, 2013) however the role of reward systems and the potential role of a neuropsychological impairment in EDs (Jauregui-Lobera, 2013) require further exploration.

The role of genetics is unclear however social transmission is evidenced both in DE (i.e. Neumark-Sztainer et al., 2008) and also in the 'cycle of discontent' put forward by the homeostatic theory, which has resemblance to the cognitive-interpersonal theory, aspects of which were evidenced in this research.

5.6.4 Models of obesity - summary

Models of obesity do not include the issue of DE and this is a serious omission. With various extreme diet and weight-loss approaches effectively promoting DE, models of obesity should address this issue and be explicit about potential risks of taking such approaches to weight loss – one can be simultaneously 'overweight' and malnourished and that brings with it additional health issues. 'The obese' are not perceived in a positive light in society, subjected to stigma across a range of contexts, often internalising this stigma, and this adds further barriers (i.e. Tomiyama, 2014; Himmelstein et al., 2015). It is fair to say that we lack a full understanding of obesity. BMI is acknowledged as a good assessment of size but not health (i.e. Sharma, 2017) and we lack definitions of 'excess' fat, and the mechanisms of how the location of 'excess' fat increases risk for specific conditions. However, models of obesity such as the homeostatic theory, are more

comprehensive, taking into account multiple factors and situating obesity within relevant contexts. What arises from such theories is the suggestion that a co-ordinated, multi-agency approach is required: healthcare does not bear sole responsibility. What we continue to see is a placing of blame, a ‘discourse of culpability’ which is neither accurate nor helpful and a continued push from healthcare (i.e. NICE, 2014) for individuals to diet, the evidence of which is poor in terms of long-term outcomes. Can we truly say that we are abiding by the Hippocratic oath to ‘do no harm’?

5.6.5 Models of DE?

Drawing a stark distinction between mental and physical health issues is starting to be seen as a less productive stance. Mental health diagnoses are not straight-forward, indeed they are problematic and the subject of much debate, but we are also recognising the role of emotional and psychological health in improving and maintaining physical health – physical and mental health recognised more as a package deal, inextricable from one another. Considering the inability of models of ED and obesity to provide a clear explanation of ED/DE and the lack of understanding around the issue of obesity, the apparent emphasis on the appearance of health and the implicit condoning of extreme dieting measures, should we be working on a comprehensive contextualised model of DE that pulls on resources other than just healthcare, to address what would appear to be a truly significant problem? The impact on individual health and wellbeing alone suggests that there is a need for an alternative approach, but the burgeoning costs to the healthcare system and wider economy may, in fact, demand such a rethink, and think-tanks such as The Health Foundation (2018) are suggesting approaches along these lines with their ‘health in all policies’ guidelines.

Creating one model which could accommodate the complexity inherent in EDs and/or the issue of obesity, covering the various contexts and engaging multiple agencies would be challenging. Holding the current models more ‘lightly’ in the interim may provide a more productive and inclusive approach to weight and eating disorders, offering the potential for more comprehensive assessments and individual, transdiagnostic, tailoring of plans for appropriate treatment: the individual must be at the centre.

5.7 Returning to the research questions

Inviting individuals across the weight spectrum with experience of DE to participate in this research enabled an exploration of their experiences within society and healthcare.

Shared experience was the norm across the contexts explored: families played a central role, both in 'setting the scene' and in recovery; healthcare interactions were difficult for all individuals, with varied responses suggesting a need for either a better understanding of, or improved responsiveness to, DE; experiences across the formal social contexts (work and school) indicated the opportunity for improvement; and the informal social context was seen as mixed. These findings receive support from and are connected to current research in these areas and add weight to the suggestions made for improvements across these areas.

The impact of different weight presentations within healthcare was evidenced whereby weight appeared to have been used as a trigger for care pathways but also a means of assessing the severity of the mental distress - a physical indicator. This suggests that HCPs may be placing undue emphasis and importance on visual indicators, especially weight. With the degree of distress as well as the less obvious (and non-visual) behavioural aspects for DE, a reliance on visual indicators is not in the best interests of the patient. Where individuals at higher weights described DE to the HCP, their weight was seen to place them 'low down the list' of priorities for treatment. Whether this is a perception originating in the HCP or an indicator of the scarcity of service provision is unclear, although the participants' narratives suggested elements of both. Regardless, it was clear that participants weights were 'getting in the way' of accessing the treatment they needed.

The appearance of health appeared to stand in the way through the medium of weight presentation and the appearance of coping and functionality across the explored contexts - family, healthcare, socially - complexity judged simplistically through appearance. In response to their experiences, participants felt that education and training were key areas for improvement - to improve general awareness of these issues, to improve support for young people in general (creating opportunities for connection and open communication), to create work environments that supported health - reducing what was seen as a reliance on visual signs of coping and functionality. Within healthcare, participants felt there was a need to train HCPs around DE particularly. This research suggests that we cannot categorise individuals of any weight, nor make broad generalisations. Rather it indicates that the issue of weight, in terms of health and in terms of mental health and EDs/DE is somewhat of a 'red herring'.

5.8 Reflections on the research

5.8.1 Issues of quality

The eight 'Big Tent' criteria (Tracy, 2010) were used as the quality framework for this research (appendix 8.3). In addition to the criteria, Tracy stresses the need for transparency and the importance of the researcher not covering 'blemishes' with post-hoc rationales. In the light of the need for such transparency the strengths and blemishes of the current research will be explored.

The worthiness and relevance of the topic are clear (i.e. Beat, 2013, *Endangered Bodies*, McKinsey, 2014, PHE, 2015) and there are demonstrations of rigour (e.g. theoretical constructs, time in the field, process) however the sample was biased in terms of ethnography as well as regarding knowledge of DE/EDs through the use of an ED charity to facilitate recruitment. This was acknowledged though and it is questionable whether it is possible to gain insight into experiences of DE without the participant being aware of their own experience in this regard. The sincerity is demonstrated through reflexivity and transparency throughout, however, although there was use of thick description and triangulation, criticism regarding credibility can be made through the lack of multivocality (demographically) and member reflections. Although the issue of member reflections can arguably be justified with the frame of ethics regarding sensitive research, it is acknowledged that there are alternative approaches that could have facilitated improved credibility.

The illustrations of the themes provides resonance through the narratives of the participants. That the participant group encompassed a broad range of experiences, age ranges, diagnoses and situations enables naturalistic generalisations and the findings, covering the weight spectrum, are transferable to HCPs, educators, workplaces, community and family members. The contribution of this research holds significance to clinical practice, education, public health, policy and families, underlining, as it does, the impact of assumptions based on visual indicators and weight and through questioning whether we are placing too much emphasis on the appearance of health to the neglect of the reality of health. Suggesting the need for further progress regarding co-production there are also clear grounds to seek greater depth of connection and understanding of individuals that moves beyond an appearance of coping and/or functionality.

The ethics of this research were scrutinised very closely at all stages of the research, with alterations made in response to PPI and supervisory advice as well as with regard to the

sensitive nature of the research. Ethical decisions were justified and adhered to throughout with the safety of both participant and researcher made paramount. Finally, the meaningful coherence of the research is apparent in that it answers the research questions by means of appropriate and relevant methods and procedures, connecting with theory and current research. From conception, it was hoped that this research would be judged as 'good qualitative research' having broad applicability and utility, seeking to more accurately represent the voices of the individual, to shed light on where weight-based assumptions may be influencing decisions and systems and how we may lay bare such assumptions:

"Good qualitative research is like a crystal, with various facets representing the aims, needs and desires of various stakeholders including participants, the academy, society, lay public, policy makers, and last, but certainly not least, the researcher." (Tracy, 2010; Ellingson, 2008).

5.8.2 Researcher reflections

In seeking themes across the narratives there was a challenge in terms of wanting to still recognise the individual story, valuing and acknowledging the personal detail and experience and establishing what themes were apparent. Looking across the contexts it was possible to see that the contexts themselves held potential in terms of explanation of origin as well as in terms of recovery. Aspects of all the models were apparent – how these come together suggests a trans-theoretical approach to understanding is required (as well as a transdiagnostic approach to treatment).

5.8.2.1 Reflections on the role of researcher

Working clinically, as I do, with people with mental and physical health issues, it was challenging at times to not engage on that level. Where individuals were talking about their care package and what was being offered, I felt a desire to advise on other ways of getting the connections and access to treatments that they wanted. Where people had had a long run of unproductive contact with services I wanted to suggest a framework for moving forward. The urge to want to work with the individual to explore ways forward was present in all my interviews. The clinical work certainly was useful in terms of reflecting on the positives in the journeys of each person. At turns I felt angry, hopeful, admiration, frustration - the additional safeguards for myself

proved to be an important addition to the preparation for this research and I would counsel other researchers embarking on research in this area to do the same.

I regret that I was unable to represent the individual narratives in more detail in order to honour their stories as they were very powerful: every person I spoke to had something new to tell me. All of the stories contained a new revelation, a new shocking response from a school or HCP or parent etc.. I am left with the belief that there is much more work to do in this area if we are to improve our understandings and treatment of EDs and DE and that early intervention and prevention are key.

5.9 Future directions

The response from individuals with experience of DE across the weight spectrum to this research was far greater than I imagined. It resulted in having to make difficult decisions about sampling, representation, and analysis. I have taken a particular approach that conveys the themes while respecting the individual narrative. What is clear from this research is that there is far more work to do in this area and that the current research represents the starting point for multiple smaller research projects.

The devastating effects of EDs, DE and the immense impact of obesity share a foundation in food and bodies; the extremes represent high levels of physical health risk but the psychological distress is apparent across the spectrum. The result of poor nutrition across an extended period cannot be underestimated in terms of physical health alone, but when we consider the impact of poor nutrition on mental health, we are actually looking at very poor health and wellbeing outcomes and higher healthcare costs ultimately.

If we fully embrace the moves in healthcare towards a more preventative stance, early intervention, as well as the movement towards working with rather than 'delivering healthcare to' patients, there is scope for the development of better approaches and treatments that will deliver the improved health and wellbeing outcomes as well as lower healthcare costs. Maximising the 'health-span' of the population has to be a priority.

6 Conclusion

Our approach to healthcare is evolving. Although, originally, we sought medical expertise to address and 'correct' illness and disease, whereby the 'compliant patient' 'received' healthcare from the expert/doctor (evident in the concept of the 'active eye and mute body', Foucault, 1973), more current thinking is moving towards co-production (i.e. Crimlisk, 2017; Chambers et al., 2017; Batalden et al., 2016) and the importance of 'working with' rather than 'delivering healthcare to' patients. This acknowledges and harnesses the expertise of the patient. This requires an attitudinal shift on both sides. With an awareness of the role of appearance in health, we have the necessary insight and opportunity to enable HCPs to overcome the deep-rooted pull to appearance. This requires a shift in training and delivery protocols: a system-wide change. The role of appearance in schools, where students who appear to be coping are assumed to BE coping, does not address the need to develop the individual, including physical and mental health, through education. The role of appearance in families, where larger bodies are seen as 'problems to be addressed' and smaller bodies as requiring medical input, is also problematic and rooted in cultural ideas around 'right/wrong bodies', how to perform the appearance of health, as well as issues within families. By routinely adopting an approach that looks to the complexity, relying less on aspects of appearance such as weight, the potential for constructive engagement increases and with it, ultimately, improvements in health and wellbeing, longer 'health-spans' and a reduction of healthcare costs in the longer term.

It is not the place of the state to 'nanny': but it is the place of the state to provide fair access, that supports all, providing policies and systems that are grounded in the reality of health-promoting and health-maintaining behaviours, not just the appearance of health.

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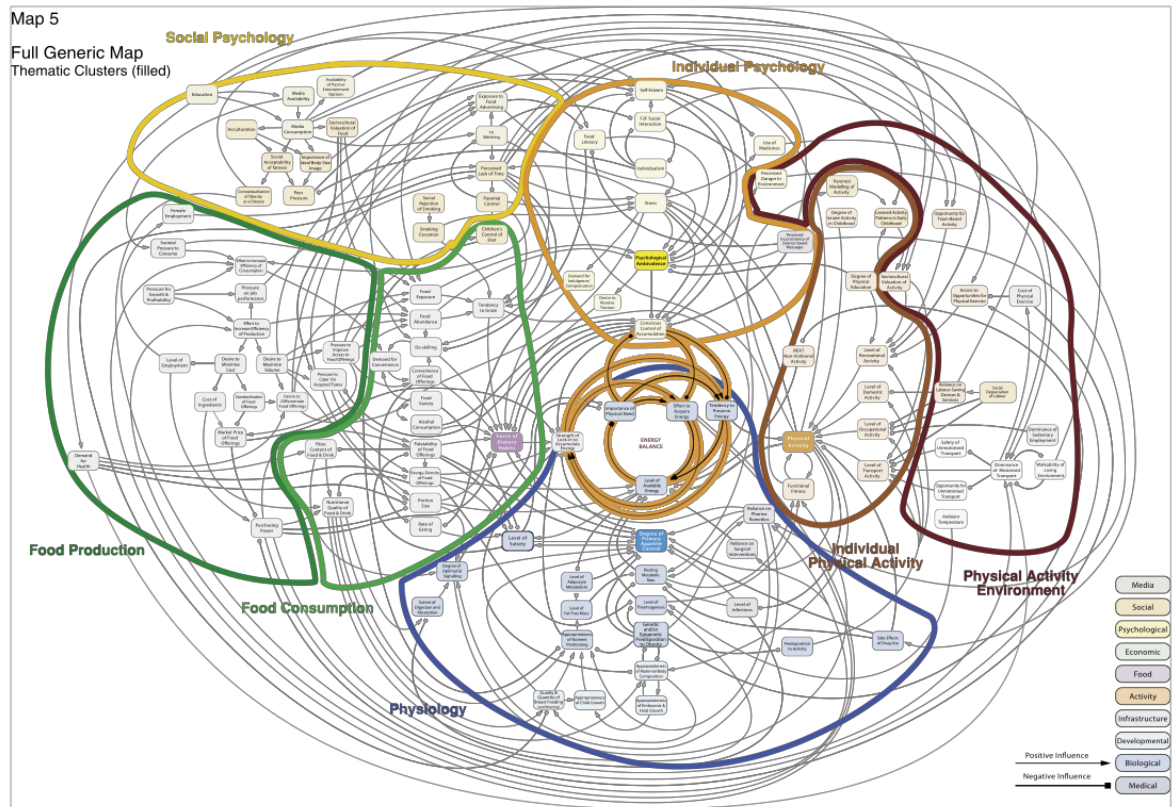
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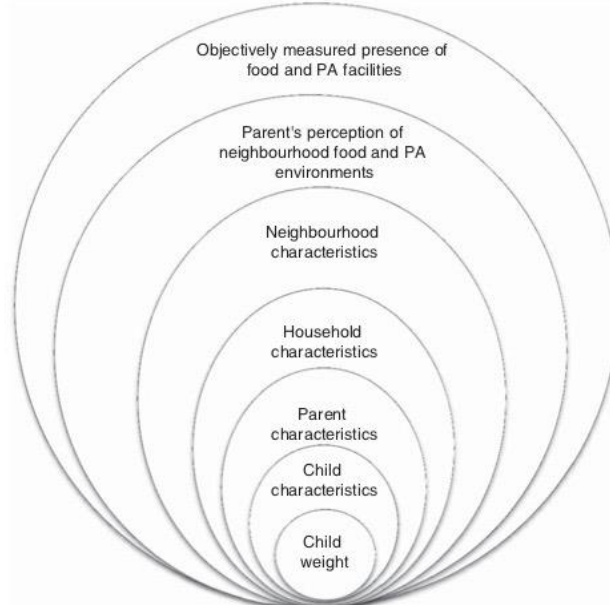
8 Appendix

8.1 Systems map from Foresight report (Butland et al., 2007)



8.2 Social-Ecological Model

Indicating the layers influencing a child's weight status (Ohri-Vachaspati et al., 2013)



8.3 “Big-Tent” criteria

Table 5

Summary of approach to meeting the ‘Big Tent’ quality criteria

<u>Criteria</u>	<u>Evidence main location</u>	<u>Brief summary of evidence</u>
Worthy topic	Introduction	Arguments are explored within the introduction around the social and personal significance of this research.
Rich rigour	Introduction, methodology, analysis	The research draws on a number of theories and models, presenting a clear justification for methodological decisions (see also appendix 8.3)
Sincerity	Methodology	The positioning of the researcher is made clear throughout and there is transparency regarding methodological decisions and process.
Credibility	Analysis and discussion	(see also appendix 8.3)
Resonance	Analysis and discussion	(see also appendix 8.3)
Significant contribution	Analysis and discussion	(see also appendix 8.3)
Ethical	Methodology	Particular attention has been paid to ethical considerations at all stages, taking into consideration that the topic of study is of a sensitive nature.
Meaningful coherence	Introduction, methodology, analysis and discussion	The connections between the theoretical basis, environments, methodology and analysis decisions. (see also appendix 8.3)

8.3.1 Worthy topic

The topic of the research is relevant, timely, significant and interesting.

This research attempts to “...confront seriously and thoroughly the problems and issues...” (Lee & Renzetti, 1993) of disordered eating across the weight spectrum. With the problematic perceptions and assumptions regarding responsibility and health, a more nuanced understanding in this area is required as we are, as HCPs, to provide an appropriate and effective response to individuals with disordered eating. The current diagnosis-treatment pathways leave many individuals outside of the scope of services yet STILL living with the psychological distress of disordered eating AND the physical risks associated. In terms of reducing healthcare costs in the medium to longer term, as well as the costs to community and economy, we need to work towards better recognition of these risks and better treatments and interventions to improve health and wellbeing outcomes. With the financial and personal costs of disordered eating across the weight spectrum, the inconsistency both in terms of provision and as regards following guidelines, and the shame and stigma attached, in particular to the extremes of weight presentation, gaining additional insights into the development, maintenance and treatment of disordered eating has never been more timely, significant, relevant and interesting.

8.3.2 Rich Rigour

The study uses sufficient, abundant, appropriate and complex theoretical constructs, data and time in the field, sample(s), context(s), data collection and analysis processes.

“High quality qualitative research is marked by a rich complexity of abundance” (Tracy, 2010, p84) and this is reflected in the analysis of these data. The theoretical constructs underpinning this research include the models of disordered eating (socio-cultural, cognitive-interpersonal, etc.) as well as the ontological and epistemological positions (critical realist and contextualism – see additional section on ontological and epistemological position). From the epistemological stance of contextualism, the experiences across different contexts were analysed, using Thematic Analysis (Clark & Braun, 2006). The initial questionnaire was open for XX weeks and promoted across social media, using Twitter and Facebook, with the support of B-eat (the UK eating disorder charity). Semi-structured interviews were used to guide the data-gathering across the contexts without placing too much restriction on interviews regarding participants’ own relating of their experiences. Interviewees were selected to be representative of both age-range and frequency data within the four BMI categories (as defined by the NHS). Each interview was transcribed by the interviewer, as a scoping exercise, to provide the most thorough grasping of the individual narratives and to better progress the analysis. The analysis software, NVivo, was used, initially generating nodes for the different contexts. These context nodes were then analysed to determine the themes within the contexts. Themes were analysed across the data set but attention was also paid to the individual narratives of the participants, providing a rich and nuanced understanding of participant experiences, giving voice to the ‘patient’ across contexts.

8.3.3 Sincerity

The study is characterised by self-reflexivity about subjective values, biases and inclinations of the researcher(s) and through transparency about the methods and challenges.

Self-reflexivity: my reflections on coming to this research includes my experience with patients, my views on the diagnostic criteria needing to be met prior to receiving validation and treatment, my perceptions of the mis-match between our understanding of the causes of obesity and the cultural, societal and healthcare response; a deep dissatisfaction with the current provision and approach/response to disordered eating across the weight spectrum. This is woven throughout the report.

Transparency: Seale (1999) asks for a research audit process providing “...a methodological self-critical account of how the research was done.” (p468). The research audit trail, documenting each decision, offers honest critique throughout.

8.3.4 Credibility

The research is marked by thick description, concrete detail, explication of tacit (non-textual) knowledge, and showing rather than telling, triangulation or crystallisation, multi-vocality, and member reflections.

Thick description: “...things get bigger, not smaller and tighter, as we understand them.” (Gonzalez, 2000, p629). The complexity of the data is illustrated in the quotes for each theme and the exploration of a number of themes and sub-themes within each context, noting where there are clear differences in the different weight categories and/or for males and females.

Crystallisation and triangulation: I can establish crystallisation by use of the B-eat data on treatments (availability and accessibility) and the data on weight stigma in healthcare, This, I hope, creates a complex, in-depth understanding whilst not making claims to be comprehensive.

Multi-vocality: Particular multi-vocality from the genders and across age-range – limited in terms of race and no exploration across sexuality or class. However, there is also multi-vocality in terms of the weight spectrum as there are representations from all four BMI categories.

Member reflections: This has not been undertaken with this research. Whilst acknowledging that this would enhance credibility further, the time restrictions made this impractical. However, future research would seek to include member reflections. All participants elected to have a summary of outcomes – my feedback from this will be stored securely for potential use (with permission from participants).

8.3.5 Resonance

The research influences, affects, o moves particular readers or a variety of audiences through aesthetic, evocative representation, naturalistic generalisations, and transferable findings.

Through Transferability and naturalistic generalisations. The experiences across the contexts in terms of creating an understanding of self, of origin/cause, of receiving/not receiving validation and treatment, of assumptions made around health in terms of appearance and weight are transferable and may be generalised to a broader area of health (in relation to appearance and weight).

8.3.6 Significant Contributions

The research provides a significant contribution conceptually/theoretically, practically, morally, methodologically and heuristically.

By exploring experiences across the weight spectrum, across a range of contexts, this research sheds light on areas where we can improve our identification and ability to offer effective interventions and means of slowing down or heading off the development of and entrenchment within DE/ED.

Theoretically significant: Through relating the analysis to current theories of ED and obesity the research offers insight to individuals' perceptions and experiences to critique these theories.

Heuristic significance: Many research projects focus on AN and BN or clinical populations. Broadening the scope to include the entire weight spectrum and populations without diagnoses will increase our understanding of DE/ED.

Practically significant: Adds to evidence that wait times, being passed between services, makes the condition worse. Also contributes to the argument for transdiagnostic approaches and the need to work with the 'whole person' from a biopsychosocial perspective.

8.3.7 Ethical

The research considers procedural ethics, situational and culturally specific ethics, relational ethics and exiting ethics.

(inc. self-reflexivity and multi-vocality). Emphasis places on the sensitive nature of the research and repeated references to rights to withdraw, of anonymity and confidentiality, including a cautious approach to the use of quotes to avoid possibility of identification.

Procedural ethics: received ethical approval through the university ethics board.

Participants made aware of intent to publish and rights to withdraw, that participation was voluntary and participation cannot influence in terms of receiving treatment – this was done on multiple occasions across the questionnaire, contact with participants about the interview and preceding and following the interview. All data were kept on a password protected PC (audio data and transcripts to be destroyed subsequently). No

identifying data were recorded other than demographics and email address; this data was also kept secure in the same way.

Situational ethics: Consideration was given, on the basis of the sensitive nature of the subject matter and the potential variation in terms of recovery status, to the possibility of distress during the interview. A safeguard was brought in, asking participants to provide a contact number for a 'supportive other' as a precaution. All but one participant provided this. There was no use of any of these contacts across the research. At request to interview, several participants retracted agreement to interview in consultation with the researcher due to personal circumstance.

Relational ethics: Relational ethics were established by the conduct of the researcher across contacts with participants, providing validation, positive reflection on recovery and encouragement in addition to agreeing to sharing a summary of research outcomes (offered to all participants and accepted by all).

Exiting ethics: Care was taken regarding the use of quotes to both protect identity but also to preserve the context of the quotes. All participants were reminded of intent to publish, anonymity and confidentiality and also that they could contact the researched subsequently regarding their interview.

8.3.8 Meaningful coherence

The study achieves what it purports to be about, uses methods and procedures that fit its stated goals, meaningfully interconnects literature, research questions/foci findings and interpretations with each other.

This research aims to create a more nuanced understanding of disordered eating by encompassing the weight spectrum, to include and offer critique of the problematic perceptions of responsibility and health in particular reference to appearance and weight. By interrogating the data, common themes were apparent as well as differences in terms of experiences that were predicated on weight presentation and gender. As such, the research provides insight into the ways these perceptions and assumptions impact on the individual in terms of recognising, validating and offering appropriate intervention and support. The research further offers a suggested cross-theoretical explanatory framework for DE/ED which acknowledges the broader debate on 'right/wrong bodies', implicit and explicit cultural expectations of body size, and assumptions built around the appearance of health (with emphasis on weight).

8.4 Research audit trail

Table 6

Research audit trail

<u>Decision type</u>	<u>Choice made</u>	<u>Rationale</u>
Subject area	Disordered eating across the weight spectrum	Disordered eating is not reliably recognised in weight presentations such as 'healthy' or 'overweight/obese' yet disordered eating exists among these individuals. Weight appears to 'get in the way' of recognising the distress and the dangers of disordered eating practices. The guidelines appear to have a more 'acute' model of these issues when research acknowledges the long-term nature of change and recovery regarding weight and disordered eating.

Choice of PPI	B-eat	<p>As a highly respected charity for eating disorders with a track record of supporting research as well as the recognition of disordered eating existing across the weight spectrum (with support groups for emotional eating), Beat were the first and most obvious choice for this research. Their experience with individuals with disordered eating and with researchers meant that their perspective would be highly informed and representative of the target populations views and best interests.</p>
Ontological position	Critical realism	<p>With disordered eating there are clear risks associated with the extremes of weight as well as the practices (such as binge/purge). In addition, there are influences from the cultural stance on body-image and the role of food and fashion manufacturers. However, the individual perception and response to these realities is subjective and open to interpretation. How much one is impacted by these effectively 'concrete' cultural aspects is varied. Critical realism is a 'best fit' for the subject. It is also the approach that I align myself with philosophically as a researcher. My own journey of personal identity is something I understand within the critical realist framework.</p>
Epistemological position	Contextualism	<p>Contextualism is concerned with understanding how individuals make meaning of their experiences within contexts. Without an assumption of a single reality, it allows us to accept that people make meaning of their experience as well as noting that social context impinges on these meanings. With the socio-cultural model of disordered eating, the contextualist epistemology is a good fit.</p>
Methodological choice	Interview following basic questionnaire	<p>I had initially wanted to compare the traditional health care 'snap shot' of an individual with their own experience by using the standard questionnaires used in health care to assess disordered eating and its more common co-morbidities. Through discussion with my supervisor, with my reviewers in my progression viva and through PPI with the organisation targeted for support with recruitment, I dropped the questionnaires due to uncertain risk. Working clinically, using such questionnaires felt comfortable however, using them as a ...</p>

...researcher without the back-up of a service to manage risk, the risk became too uncertain. I replaced this element with a question about individuals' experience of diagnosis in my questionnaire. In this way I moved from a mixed methods approach to a qualitative approach. As the thrust of this research is to gain insight into the personal experiences and how individuals' made sense of their narratives, using a pure qualitative methodology is sound and was supported by my supervisors.

Choice of questions	Semi-structured interview (see interview schedule)	I wanted to hear the voice of the individuals so I chose a semi-structured interview format, which would enable me to guide the interviewee to provide information on their experiences across a range of contexts, but also allowed for the participants to explain their experiences in their own way.
Analysis	Thematic Analysis	Initially, during progression, I had committed to a certain direction for this analysis (see progression report appendix 8.6) however, on receiving the initial responses to the questionnaire, and in discussion with my doctoral supervisor, we revised the participant numbers, increasing the total number of interviews from a minimum of 8 up to 16 (across female participants). The number of males responding to the initial interview were not sufficient to include with the data. In total, 15 interviews were conducted (15 females – time restrictions did not allow for a sixteenth female to be interviewed). Discussing analysis, it was decided that, as the numbers had increased so dramatically, that a change of approach was required: interviews to be transcribed and analysed 'blind' to weight category, establishing experience across the different context targeted in the interview schedule, to establish themes.

8.5 PPI

Summary of exchange with PPI organisation (B-eat) and subsequent changes made to methodology

Table 7

Summary of PPI engagement

<u>Date</u>	<u>Purpose/content</u>	<u>Action</u>
29/7/2016	Phone contact with Jonathan Kelly, Research Officer at B-eat regarding getting their support in recruiting participants for my research.	Examined requirements online: https://www.beateatingdisorders.org.uk/work-with-us-as-a-researcher
31/7/2016	Email to Beat asking for agreement in principal prior to ethical approval	
1/8/2016	Response from Beat asking for the documents without ethical approval for agreement in principal	Delay due to initial research proposal being rejected. Submitted revised proposal (approved)
23/1/2017	Sent through required documents to Beat	
1/2/2017	Response from Beat with queries	Discussed ethics and risk approval in supervision; discussed use of additional questionnaires Following discussion at progression viva (in addition to the queries from Beat) dropped the additional questionnaires
15/4/2017	Agreement in principal from Beat	Contact Beat once ethics have been approved
7/6/2017	Informed Beat of ethics approval	
8/6/2017	Sent required documents to Beat (information sheet, survey (Qualtrics), list of support lines, debrief document, copy of ethics approval from UWE	
30/8/2017	Response from Beat with additional queries	Amendments made, re-sent to Beat

4/9/2017 and minor amends to
Qualtrics survey
Notification that
research was uploaded
to their research page
and a request made for
the notification to go
onto their Facebook
page and through their
Twitter feed




APPLICATION FOR ETHICAL REVIEW OF RESEARCH INVOLVING HUMAN PARTICIPANTS

This application form should be completed by members of staff and PhD/ Prof Doc students undertaking research which involves human participants. Undergraduate and Masters level students are required to complete this application form where their project has been referred for review by a supervisor to a Faculty Research Ethics Committee (FREC) in accordance with the policy at <http://www1.uwe.ac.uk/research/researchethics>. For research using human tissue, please see separate policy, procedures and guidance linked from <http://www1.uwe.ac.uk/research/researchethics/policyandprocedures.aspx>

Please note that the process takes **up to six weeks** from receipt of a valid application. **The research should not commence until written approval has been received from the University Research Ethics Committee (UREC) or Faculty Research Ethics Committee (FREC).** You should bear this in mind when setting a start date for the project.

APPLICANT DETAILS

Name of Applicant*	Fiona Marfleet		
Faculty	Health and Social Sciences	Department	Psychology
Status: Staff/PG Student/ MSc Student/ Undergraduate	PG student (Doctoral)	Email address	
Contact postal address	21 Pitman Place, Wotton-Under-Edge, Gloucestershire GL12 7LA		
Name of co-researchers* (where applicable)	n/a		

*This form must include the name of the UWE Project Manager (normally the budget holder and PI)

FOR STUDENT APPLICANTS ONLY

Name of Supervisor/Director of Studies	Dr Rachel Gillibrand
--	----------------------

Detail of course/degree for which research is being undertaken	Professional Doctorate in Health Psychology
Supervisor's/Director of Studies' email address	[REDACTED]
Supervisor's/Director of Studies' comments	<i>I support this study.</i>
<p>For student applications, supervisors should ensure that all of the following are satisfied before the study begins:</p> <ul style="list-style-type: none"> <input type="checkbox"/> The topic merits further research; <input type="checkbox"/> The student has the skills to carry out the research; <input type="checkbox"/> The participant information sheet is appropriate; <input type="checkbox"/> The procedures for recruitment of research participants and obtained informed consent are appropriate. 	

PROJECT DETAILS

Project title	What's weight got to do with it? An exploration of experiences of disordered eating across the weight spectrum		
Is this project externally funded?	No		
If externally funded please give PASS reference	n/a		
Proposed start date for the research	April 2017	Anticipated project end date	January 2018

Fieldwork should not begin until ethics approval has been given

DETAILS OF THE PROPOSED WORK

<p>1. Aims, objectives of and background to the research</p>
<p><i>This should provide the reviewer of the application with sufficient detail to allow them to understand the nature of the project and its rationale, and the ethical context, in terms which are clear to a lay reader. Do not assume that the reader knows you or your area of work. You may provide a copy of your research proposal in addition to completing this section. Please try to keep within 500 words.</i></p>
<p>"What's weight got to do with it?" This research questions the use of weight as a signifier for health in the assessment of disordered eating, examining experiences of disordered eating across the weight spectrum. NHS costs regarding eating disorders (EDs) are estimated at 3.9bn (B-eat, 2015) and regarding obesity are estimated at 6bn (McKinsey and Co, 2014). There are associated economic and personal costs to both conditions; clearly, the costs indicate the importance of this issue. ED treatments manage the physical risks as well as providing a range of psychological treatments but treatment provision across the country is not</p>

consistent, with a significant number of services still using weight as a treatment criterion (McCubin, 2016). Treatment for 'excess' weight is 'patchy' (Public Health England, 2015, Capehorn et al., 2016) and also has a weight criterion for access (NICE, 2014). This places an emphasis on weight as a signifier of health. Fixation on shape and weight as a means of determining self-worth is an area of overlap for EDs and overweight, with shame, distress and stigma being factors which negatively impact on quality of life among both populations (Frank, 1991; Cook, 1994, Farhangi et al., 2016; Carels et al., 2009) also acting as a barrier to effective treatment. The role of society in both EDs and overweight/obesity is well-documented (McQueen, 2001; Gard, 2009, Stice, 1994). EDs and obesity have common aetiological factors (Neumark-Sztainer, 2009, Goldschmidt et al., 2015) and shared comorbidities (Fox & Goss, 2012) yet 'the obese' are portrayed as a homogenous group with an emphasis on personal responsibility, the 'discourse of culpability' (McQueen, 2001) placing a heavy burden on individuals. Clearly this is problematic.

This emphasis on weight detracts from the more appropriate focus of health (The Health Foundation, 2017; Cadenhead et al, 2012). Certainly there are weights at which there are greater health risks as well as weights at which those risks become dangerously high. However, the conception of health across weights is not commonly discussed. An individual classed as falling outside the 'healthy BMI' (and 'overweight') can be healthier in terms of risk than individuals within the 'healthy BMI' bracket (Blair, 2012); weight itself cannot be used as a signifier of health yet it serves as a key gatekeeper to treatment.

This research aims to explore the individual experience of disordered eating across the weight spectrum ('healthy' and 'unhealthy' classifications) to develop deeper understandings in this area creating the potential to develop and provide appropriate support and treatments that are not predicated on weight. Accepting that greater risks are present at the extremes of weight presentation, weight is not a global signifier of health: this research also hopes to add to the debate around the concept of the 'healthy body' and shift greater focus to this.

2. RESEARCH METHODOLOGY TO BE USED

You should explain how you plan to undertake your research. A copy of the interview schedule/questionnaire/observation schedule/focus group topic guide should be attached where applicable.

A qualitative approach will be used, preceded by a questionnaire gathering basic demographics (using Qualtrics, see attached)

Qualitative data

Qualitative data will be gathered via a semi-structure interview. Although, as Dickson-Swift et al. (2008) point out, there is a risk of preventing participants from telling their story if too much structure is used when researching sensitive subjects, a few guiding questions will be used. The questions will cover the individual's perceptions of:

- the nature and experience of their disordered eating/weight issue;
- their perception of the aetiology of these issues;
- diagnoses and, in particular, any diagnosis they have been given;
- the treatment they received (from medical professions);
- the treatment from society (including family, friends);
- how they feel treatment could be improved.

3. SELECTION OF PARTICIPANT

You must indicate if any of the participants in your sample group are in the categories listed. Research involving adult participants who might not have the capacity to consent or who fall under the Mental Capacity Act must be reviewed either by an NHS Research Ethics Committee or the [National Social Care Research Ethics Committee](#).

If your proposed research involves contact with children or vulnerable adults, or others of the specified categories below, you may need to hold a valid DBS check. Evidence of a DBS check should take the form of an email from the relevant counter signatory confirming the researcher has a valid DBS check for working with children and/or vulnerable adults. It is the responsibility of the applicant to provide this confirmation.

Members of staff requiring DBS checks should contact Human Resources [REDACTED] DBS checks for students are usually organised through the student's faculty, but students in faculties without a DBS counter signatory should contact Leigh Taylor ([REDACTED]).

I have agreement in principle to support the study from the eating disorder charity, Beat. They cannot provide full agreement until I gain ethical approval for my research.

The data being analysed will be that arising from the interviews. As such, the sample size is determined from a qualitative perspective; I require a minimum of 8 and a maximum of 12 participants. This was agreed within the context of the research proposal (see attached).

Participants will have experience of disordered eating and, as such, are classed as vulnerable. I have provided information (in the information sheet) regarding the nature of the questions in the interview, and alerted them to the possibility that the act of reflecting on their experiences may bring up some difficult emotions (although the questions themselves are not intended to cause distress – see attached interview questions/topic areas).

I hold a current DBS certificate (working currently both within adult community mental health services and also holding a placement at the Specialist Weight Management Service at Gloucester Royal Hospital – see attached evidence for DBS certificate). I have provided lists of support lines, should participants become distressed, including Beat, and a debrief listing those sources of support should participants withdraw at the questionnaire phase (see attached).

I have developed a contingency plan, should a participant become distressed during the interview phase of the research, which is incorporated into the information sheet under the 'What do I have to do?' section.

4. Please explain how you will determine your sample size/recruitment strategy, and identify, approach and recruit your participants. Please explain arrangements made for participants who may not adequately understand verbal explanations or written information in English

In this section, you should explain the rationale for your sample size and describe how you will identify and approach potential participants and recruit them to your study.

The data being analysed will be that arising from the interviews. As such, the sample size is determined from a qualitative perspective; I require a minimum of 8 and a maximum of 12 participants. This was agreed within the context of the research proposal (see attached).

I will be using adult participants.

Adults (male and female) with experience of disordered eating are eligible for inclusion within the study, regardless of whether they have (or have had) a diagnosis of an eating disorder from health care professionals.

Participation is also limited to those who are fluent in English.

5. What are your arrangements for obtaining informed consent whether written, verbal or other? (where applicable, copies of participant information sheets and consent forms should be provided)

Informed consent is an ethical requirement of most research. Applicants should demonstrate that they are conversant with and have given due consideration to the need for informed consent and that any consent forms prepared for the study ensure that potential research participants are given sufficient information about a study, in a format they understand, to enable them to exercise their right to make an informed decision whether or not to participate in a research study.

You should describe how you will obtain informed consent from the participants and, where this is written consent, include copies of participant information sheets and consent forms. Where other forms of consent are obtained (eg verbal, recorded) you should explain the processes you intend to use. If you do not intend to seek consent or are using covert methods, you need to explain and justify your approach. Please consider carefully whether or not you need to seek consent for archiving or re-use of data.

I have provided a detailed information sheet regarding the nature of the research, requirements from participants, details of who can take part, and a clear consent form (see attached).

<p>It has been made clear in the information sheet and consent form that participation in the study is entirely voluntary, that anonymity is assured and that the results will be used for research purposes only (and possibly publication in relevant health journals). That there is no link between participation and potential treatment provision has been stated clearly (see attached) in order to avoid possible feelings of coercion amongst potential participants; the purpose of the research, as an exploration of experiences, to improve understanding and inform potential treatment development is made clear.</p>
<p>6. What arrangements are in place for participants to withdraw from the study?</p>
<p><i>Consent must be freely given with sufficient detail to indicate what participating in the study will involve and how they may withdraw. There should be no penalty for withdrawing and the participant is not required to provide any reason.</i></p> <p><i>Please note: allowing participants to withdraw at any time could prejudice your ability to complete your research. It may be appropriate to set a fixed final withdrawal date.</i></p>
<p>The right to withdraw is made clear from the beginning within the information sheet. It is also made clear in the consent form (see attached). Voluntary participation has been stressed throughout as well as anonymity, confidentiality and the lack of influence (from involvement in the research) over provision of treatment by their health care professionals.</p>
<p>7. If the research generates personal data, please describe the arrangements for maintaining anonymity and confidentiality (or the reasons for not doing so)</p>
<p><i>You should explain what measures you plan to take to ensure that the information provided by research participants is anonymised/pseudonymised (where appropriate) and how it will be kept confidential. In the event that the data are not to be anonymised/pseudonymised, please provide a justification.</i></p> <p><i>Personal data is defined as 'personal information about a living person which is being, or which will be processed as part of a relevant filing system. This personal information includes for example, opinions, photographs and voice recordings' (UWE Data Protection Act 1998, Guidance for Employees).</i></p>
<p>There will be no identifying data in the report. Some personal information will be used to enable the arrangement of the interview phase of the research and as part of the contingency plan. Once the data analysis has been completed, all such data will be destroyed and the data anonymized within the report.</p> <p>While in use, personal data will be held on a password protected personal PC, with current firewall and antivirus protection and will not be accessed by any other individual.</p>
<p>8. Please describe how you will store data collected in the course of your research and maintain data Security and protection.</p>
<p><i>Describe how you will store the data, who will have access to it, and what happens to it at the end of the project, including any arrangements for long-term storage of data and potential re-use. If your research is externally funded, the research sponsors may have specific requirements for retention of records. You should consult the terms and conditions of grant awards for details.</i></p> <p><i>It may be appropriate for the research data to be offered to a data archive for re-use. If this is the case, it is important that consent for this is included in the participant consent form.</i></p> <p><i>UWE IT Services provides data protection and encryption facilities - see http://www.uwe.ac.uk/its-staff/corporate/ourpolicies/intranet/encryption_facilities_provided_by_uwe_itservices.shtml</i></p>
<p>All data will be stored on my password protected personal PC. No other individuals will have access to the data and all identifying data will be destroyed once the purpose of the personal data is complete (i.e. contact, interview arrangements). Following this, all data will be retained in anonymized form only.</p>

<p>Beat do not ask for data from research they support and the data will not be passed to a data archive.</p>
<p>9. What risks (eg physical, psychological, social, legal or economic), if any, do the participants face in taking part in this research and how will you address these risks?</p>
<p><i>Describe ethical issues related to the physical, psychological and emotional wellbeing of the participants, and what you will do to protect their wellbeing. If you do not envisage there being any risks to the participants, please make it clear that you have considered the possibility and justify your approach.</i></p>
<p>There are no expected physical, legal or economic risks beyond those incurred in everyday life. There is potential for psychological risk – these arise from the sensitive nature of the subject matter in general. Information regarding what to expect in the research are included in the information sheet and consent form to mitigate this possibility.</p> <p>There is the possibility of distress from the interview; discussing experiences of disordered eating may bring up some difficult emotions. A contingency plan has been developed to provide for this possibility and details of this incorporated into the information sheet. Whether completing just the questionnaire or completing the full participant requirements, a list of support lines and services to approach for support are provided.</p> <p>The possibility of social risk has been considered, as Skype and phone are methods for conducting the interviews, potentially enabling the presence of others (family, friends etc.). I will mitigate for this by asking participants to agree to conduct the Skype/phone interview in a room by themselves where they will not be disturbed.</p>
<p>10. Are there any potential risks to researchers and any other people impacted by this study as a consequence of undertaking this Research that are greater than those encountered in normal day to day life?</p>
<p><i>Describe any health and safety issues including risks and dangers for both the participants and yourself (if appropriate) and what you will do about them. This might include, for instance, arrangements to ensure that a supervisor or co-researcher has details of your whereabouts and a means of contacting you when you conduct interviews away from your base; or ensuring that a ‘chaperone’ is available if necessary for one-to-one interviews.</i></p> <p><i>Please check to confirm you have carried out a risk assessment for your research</i> x</p>
<p>The subject matter is one which has the potential to involve distressing experiences relayed by participants and this has the potential to impact negatively on the researcher. To address this concern, I have arranged with my doctoral supervisor to receive supervision, specifically for this purpose, during the interview phase of the research.</p>
<p>11. How will the results of the research be reported and disseminated?</p>
<p><i>Please indicate in which forms and formats the results of the research will be communicated.</i></p>
<p>(Select all that apply)</p> <p><input checked="" type="checkbox"/> Peer reviewed journal</p> <p><input checked="" type="checkbox"/> Conference presentation</p> <p><input type="checkbox"/> Internal report</p> <p><input checked="" type="checkbox"/> Dissertation/Thesis</p> <p><input type="checkbox"/> Other publication</p> <p><input checked="" type="checkbox"/> Written feedback to research participants</p> <p><input type="checkbox"/> Presentation to participants or relevant community groups</p> <p><input type="checkbox"/> Digital Media</p>

<input type="checkbox"/> Other (Please specify below)
12. WILL YOUR RESEARCH BE TAKING PLACE OVERSEAS?
<i>If you intend to undertake research overseas, please provide details of additional issues which this may raise, and describe how you will address these. Eg language, culture, legal framework, insurance, data protection, political climate, health and safety. Please also clarify whether or not ethics approval will be sought locally in another country.</i>
No
13. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of the Faculty and/or University Research Ethics Committee?
<i>This gives the researcher the opportunity to raise any other ethical issues considered in planning the research or which the researcher feels need raising with the Committee.</i>
No

CHECKLIST

Please complete before submitting the form

Please note: supporting documentation should include version numbers and dates


	Yes/No
Is a copy of the research proposal attached?	Yes
Have you explained how you will select the participants?	Yes
Is a participant information sheet attached?	Yes
Is a participant consent form attached?	Yes
Is a copy of your questionnaire/topic guide attached?	Yes
Have you described the ethical issues related to the well-being of participants?	Yes
Have you described fully how you will maintain confidentiality?	Yes
Have you included details of data protection including data storage?	Yes
Where applicable, is evidence of a current DBS (formerly CRB) check attached?	Yes
Is a Risk Assessment form attached? (HAS only)	Yes
Have you considered health and safety issues for the participants and researchers?	Yes

DECLARATION

The information contained in this application, including any accompanying information, is to the best of my knowledge, complete and correct. I have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my obligations and the right of the participants.

Principal Investigator name	Fiona Marfleet
Signature	
Date	2 nd May 2017
Supervisor or module leader name (where appropriate)	Dr Rachel Gillibrand
Signature	
Date	2 nd May 2017

The signed form should be submitted electronically to Committee Services:

 and email copied to the Supervisor/Director of Studies where applicable together with all supporting documentation (research proposal, participant information sheet, consent form etc).

For student applications where an electronic signature is not available from the Supervisor we will require an email from the Supervisor confirming support.

Please provide all the information requested and justify where appropriate.

For further guidance, please see <http://www1.uwe.ac.uk/research/researchethics> (applicants' information)

8.6.1 Risk assessment



GENERAL RISK ASSESSMENT FORM

Ref:

Describe the activity being assessed: Qualitative research including questionnaire and interview (An exploration of experiences of disordered eating across the weight spectrum'). The questionnaire asks for age, gender, weight, height, diagnoses given/felt, treatments received or sought. The interview aims to cover the following topics: the nature and experience of their disordered eating/weight issue; their perception of the aetiology of these issues; their views on diagnoses; views on how they were/are treated by the medical profession/healthcare system; views on how they were/are treated by friends, family, society; how they feel things could be improved. Interviews may be conducted face-to-face at UWE (if local), via Skype or on the phone. The interviews will be recorded (audio) using a plug-in/app if on Skype or using the internal recorder on the iPhone if via phone on face-to-face.	Assessed by: Dr Rachel Gillibrand	Endorsed by: Dr Jane Meyrick
Who might be harmed: Participants; researcher	Date of Assessment: 28 th April 2017	Review date(s): 28 th April 2018
How many exposed to risk: 9-13		

Hazards Identified (state the potential harm)	Existing Control Measures		Additional Control Measures		Risk Level	By whom and by when	Date completed
	S	L	S	L			
Emotional distress (participants) as a result of reflecting on their experiences of disordered eating and treatment	1	3			3	Researcher prior to, during and after the interviews.	
<input type="checkbox"/> In the information sheet and at the beginning of the interview, participants are told that taking part in the research is voluntary and that should they feel distressed during the interview, the interview will be paused. The researcher will check to see if the participant is ok and if they want to continue with the interview questions. The participant will be reminded that they are able to stop the interview at any point and this will happen if they express this wish. <input type="checkbox"/> In the information sheet and at the beginning of the interview, participants will be told that they have the right to withdraw from the study at any moment and without providing a reason for			None needed				

GENERAL RISK ASSESSMENT FORM

Ref:

<p>Describe the activity being assessed: Qualitative research including questionnaire and interview (An exploration of experiences of disordered eating across the weight spectrum'). The questionnaire asks for age, gender, weight, height, diagnoses given/felt, treatments received or sought. The interview aims to cover the following topics: the nature and experience of their disordered eating/weight issue; their perception of the aetiology of these issues; their views on diagnoses; views on how they were/are treated by the medical profession/healthcare system; views on how they were/are treated by friends, family, society; how they feel things could be improved. Interviews may be conducted face-to-face at UWE (if local), via Skype or on the phone. The interviews will be recorded (audio) using a plug-in/app if on Skype or using the internal recorder on the iPhone if via phone on face-to-face. I will be lone-working but will receive supervision from my doctoral supervisor.</p>	<p>Assessed by: Dr Rachel Gillibrand</p>	<p>Endorsed by: Dr Jane Meyrick</p>
<p>Who might be harmed: Participants; researcher</p>	<p>Date of Assessment: 28th April 2017</p>	<p>Review date(s): 28th April 2018</p>
<p>How many exposed to risk: 9-13</p>		

Hazards Identified (state the potential harm)	Existing Control Measures	S	L	Risk Level	Additional Control Measures	S	L	Risk Level	By whom and by when	Date completed
Emotional distress (participants) as a result of reflecting on their experiences of disordered eating and treatment	<input type="checkbox"/> In the information sheet and at the beginning of the interview, participants are told that taking part in the research is voluntary and that should they feel distressed during the interview, the interview will be paused. The researcher will check to see if the participant is ok and if they want to continue with the interview questions. The participant will be reminded that they are able to stop the interview at any point and this will happen if they express this wish. <input type="checkbox"/> In the information sheet and at the beginning of the interview, participants will be told that they have the right to withdraw from the study at any moment and without providing a reason for	1	3	3	None needed				Researcher prior to, during and after the interviews.	

overlap in experiences, and an already existing acceptance that there is scope for researchers in eating disorders and obesity to work together - we should place greater emphasis on understanding the origins of disordered eating and reduce the emphasis on weight in order to better recognise the distress that disordered eating causes for an individual, regardless of weight presentation, and to work towards better provision in terms of support and treatment for those affected.

Background and literature review

Weight is a personal issue, but one that is judged freely in society with an emphasis on the 'thin-ideal' and stigma regarding 'excess' weight. Although the balance within the body of muscle and fat, levels of cardiorespiratory fitness, and the general function of the body in the context of lifestyle factors provide far better indicators and predictors of health, the general focus is on weight, with Body Mass Index (BMI) being a significant factor in access to treatments for eating disorders as well as obesity. There is a disparity regarding the way we view and treat individuals classified as obese, and those that are diagnosed with an eating disorder (ED) such as anorexia nervosa (AN) or bulimia nervosa (BN). Within media rhetoric, as well as in general in society, the 'overweight' are shamed, assumed to be unhealthy and personally responsible. 'Obesity' is used as a pseudo-diagnostic term, distracting away from investigation as to the causes. The complexity around EDs and obesity is accepted and broad assumptions should be avoided, however, shape and weight concerns and eating behaviours are features that appear across both these areas.

Costs

A B-eat commissioned study in 2015 estimated the direct costs to the NHS of EDs at around 3.9bn. Comparatively, costs to the NHS regarding obesity have been estimated at 6bn (McKinsey and Co, 2014); the human-generated economic burden, places obesity at number 2 in the UK, just below smoking. The personal costs to individuals, family and communities, arising from EDs and obesity is difficult to measure; the distress and stigma creates additional psychological burdens. Clearly, the costs indicate the importance of this issue.

Guidelines for treatment

For EDs, treatment covers management of the physical risks of low weight/binge-purge cycles and also addresses the psychological aspects. A range of psychological treatments are recommended, including Cognitive Analytical Therapy (CAT), Cognitive Behavioural Therapy (CBT, and the special versions for BN and Binge Eating Disorder (BED)), Interpersonal Therapy (IPT), focal psychodynamic therapy, and family interventions. The recommended length of these treatments for outpatients is at least 6 months and for those coming from an inpatient stay, at least 12 months (National Institute for Clinical Excellence, NICE, 2004).

The NICE obesity guidelines (2014) recommend a four-tier treatment model: tier 1. Behaviours – universal – messages about healthy weight and lifestyle; tier 2. Lifestyle weight management services – some commercial providers (i.e. WeightWatchers, Slimming World) and some NHS provided services. These are typically limited to around 12-14 weeks; tier 3. Clinician-led multidisciplinary team (MDT) – again, a mix of commercial and NHS providers. At this tier, pharmacological approaches are considered; tier 4. Clinician-led MDT with a high likelihood of bariatric surgery. Capehorn et al. (2016) noted that the tiered system was not being implemented consistently across the country and that a 'postcode lottery' existed regarding treatment provision.

Treatment provision

Treatment provision for EDs is far from consistent across the UK; some areas are still using weight as a treatment criterion (McCubbin, 2016) which, it has been recognised, adds to the problem for ED patients seeking treatment – "It made me feel like I wasn't good enough at my eating disorder... It made me feel like I would have to get better at it." McCubbin found that, of the 44 mental health trusts who responded, one-third said they still used weight as a treatment criterion.

This places an emphasis on weight as a determinant of health, an emphasis which is misplaced and potentially damaging for patients with EDs (i.e. McCubbin, 2016) as well as those classified as obese, where BMI is the main factor determining access to treatment. NICE guidelines (2004) are clear that BMI alone is not an adequate treatment criterion for EDs. And we know that, regardless of weight, patients can be engaging in binge-purge cycles and other forms of disordered eating. We also know that factors such as cardiorespiratory fitness moderate health risks associated with overweight (Blair, 2009). Being at a 'healthy weight' does not necessarily mean you are healthy.

For weight management, tier one and two services are present in 72% of local authorities, although services such as exercise and commercial weight management schemes on prescription are not guaranteed. At tier 3 and 4, only 21% of CCGs reported service provision (Public Health England, PHE, 2015) leaving much of the country without provision (although PHE had poor response for these tiers so the actual provision may be better than this). The referral guidelines for access to these tiers are based on BMI (and co-morbidities). As previously noted by Capehorn et al. (2016), the guidelines are not being implemented consistently across the country.

Treatment provision for EDs and weight management are inconsistent; the gateway to these services are based in large part on BMI.

Underlying complexity

Origins

The origins of EDs and obesity are accepted to be complex and varied (Foresight, 2007) but there are factors amongst ED aetiologies that are also found among individuals with weight management issues (Neumark-Sztainer, 2009, Goldschmidt et al., 2015) yet 'the obese' are portrayed as a homogenous group with an emphasis on personal responsibility, the 'discourse of culpability' (McQueen, 2001) placing a heavy burden on individuals. Clearly this is problematic; it neglects many relevant factors such as origins, maintaining factors and varying fitness levels.

Shape and weight

Fixation on shape and weight as a means of determining self-worth is an area of overlap for EDs and obesity with shame, distress and stigma being factors which negatively impact on quality of life among both populations (Frank, 1991; Cook, 1994, Farhangi et al., 2016; Carels et al., 2009) also acting as a barrier to effective treatment. The role of societal/cultural standards for body image is also well documented in both EDs and obesity (McQueen, 2001; Gard, 2009, Stice, 1994) and the role of the 'thin ideal' and expectations around body shape and size have been noted as a factor in disordered eating (Seddon & Berry, 1996). Both the sociocultural and cognitive-interpersonal models of EDs refer to the role of cultural expectations and perceived pressures to appear a certain way, with these pressures impacting on many (fuelled by the profitable 'diet industry' and the media). Whereas the sociocultural model (Stice, 1994) states that perceived pressure (from media, family, peers etc.) leads to internalisation of cultural ideals regarding body image, then body image dissatisfaction, then to disordered eating, the cognitive-interpersonal model expands on this. It suggests there are predisposing factors (cognitive rigidity, obsessive-compulsive traits and difficulties with social communication). When precipitating factors occur (teasing or bullying around weight and eating, social comparison regarding body shape, a stressful event or difficulty) this leads onto disordered eating and the cycle that maintains it (which also includes reinforcement by family members with traits that form the predisposing factors). This model also explains how, in the case of anorexia, the inadequate brain nutrition exacerbates the cognitive rigidity and obsessive-compulsive behaviours, further entrenching the individual within their disordered eating (Treasure & Schmidt, 2013). With or without predisposing factors, the pressure, or perceived pressure from various sources plays a significant role in the assessment of the body as inadequate/failing to match cultural ideals.

The emphasis on weight also detracts from the more appropriate focus of health (The Health Foundation, 2017; Cadenhead et al., 2012). Certainly there are weights at which there are greater health risks as well as weights at which those risks become dangerously high. However, the conception of health across weights is not commonly discussed. An individual classed as falling outside the 'healthy BMI' can be healthier in terms of risk than individuals within the 'healthy BMI' bracket (Blair, 2009); weight itself cannot be used as a signifier of health yet it serves as a key gatekeeper to treatment.

Co-morbidities

There are specific co-morbidities that are seen to arise often in individuals with EDs - depression, anxiety and obsessive compulsive behaviours are noted as the most common (Fox & Goss, 2012). These issues are also observed amongst individuals who struggle with weight management. There are associations between anxiety and negative self-image and negative eating behaviours (de Man Lapidoth & von Hauswolff-Juhlin, 2014), depression (Riva et al., 1998) and ED psychopathology has been observed in some individuals classified as obese (von Ranson et al., 2011).

Diagnoses

There is a 'fluidity' regarding diagnoses for EDs (Fox & Goss, 2012) whereby individuals may vary in their presentation, sometimes fitting one diagnosis and sometimes another. There are cases whereby individuals with a previous diagnosis of AN become obese, post-recovery, and instances where individuals move from being classified as obese to engaging in restrictive and extreme weight control mechanisms, moving to a diagnosis of BN or AN. BN itself is under-diagnosed (Dovey, 2010) and BED, a relatively recent addition to the DSM-5 (manual of mental disorders, American Psychiatric Association, 2013), has wildly varying prevalence estimates (7-46%) – weight is a particularly poor indicator of the underlying distress in both groups.

The complexities that cross ED and obese populations, the similarities in origins and co-morbidities, and the fluidity with which disordered eating presents suggests there is more to discover. With treatment provision for both EDs and weight management being patchy, and guidelines not being consistently implemented, research which provides more understanding in this area has the potential to play a role in the improvement of service provision. Creating discourse around weight as a signifier of health and establishing that 'the obese population' is not homogenous, but includes individuals with varying origins to their challenges, varying behaviours and presentations including those that may be classed as

'disordered', I hope to move the wider debate around obesity forwards and remove the use of 'obesity' as a pseudo-diagnostic term, paving the way for more individualised and appropriate treatment options. I suggest that the *degree* of disordered eating and the level of psychological distress should be treated as features of much greater significance with less emphasis placed on weight as a signifier of health and a gatekeeper to treatment.

Aims

To explore the individual experience of disordered eating across the weight spectrum ('healthy' and 'unhealthy' classifications) with a view to developing a deeper understanding of this complex issue. To use this knowledge to inform and provide appropriate support and treatments that are not predicated on weight. Accepting that greater risks are present at the extremes of weight presentation, but incorporating the notion that weight is not a global signifier of health: this research also aims to add to the debate around the concept of the 'healthy body' and shift greater focus to this.

Methodology

A mixed methods approach will be used combining standard questionnaires with a semi-structured interview. The standard questionnaires will be used for indicative purposes only.

Quantitative measures

An assessment of disordered eating will be followed by standard questionnaires that assess the common co-morbidities found with individuals with disordered eating (depression, anxiety and obsessive-compulsive traits). The questionnaires will appear in the Qualtrics survey online following the information sheet and provision of informed consent. The scores will be used to create an indicative diagnostic profile of the participant.

NB: All the questionnaires are freely available online and are in common use in the health service.

EDE-Q

The Eating Disorder Examination Questionnaire (Fairburn and Beglin, 1994) is one of the most commonly used tools in the diagnosis of disordered eating. It is produced with norms for scores and examines concern regarding eating, weight, shape and restraint – aspects common to both 'under' and 'over' weight individuals. The EDE-Q is a self-report version of the EDE, consisting of 28 questions concerning the past 28 days. The frequency of occurrence of symptoms are scored by the individuals. There are four subscales: restraint (1.30); eating concern (0.76); weight concern (1.79); and shape concern (2.23). The scores for the subscales are generated by adding together the ratings for the relevant questions and dividing by the number of questions in that subscale (normative scores provided in brackets; global score norm, 1.52, Mond et al., 2006). Higher numbers indicate higher symptomatology. The EDE-Q has good validity in community samples (Mond et al., 2004) and acceptable internal consistency and test-retest reliability (Luce and Crowther, 1999).

GAD-7

The Generalised Anxiety Disorder questionnaire (Spitzer et al., 2006) provides a measure of anxiety and consists of seven questions. It is commonly used within the NHS (GPs and IAPT services). A four point scale is used in each answer (0, 1, 2, 3), an overall score out of 21 being provided. It has good general reliability and validity (Lowe et al., 2008 and Spitzer et al., 2006). Scores over 10 indicate the need for further investigation and, potentially, treatment (an indicator of Generalised Anxiety Disorder). Spitzer et al. (2006) found that approximately 90% of the population have scores of less than 10.

PHQ-9

The Patient Health Questionnaire, created by Kroenke et al. (2001) consists of nine questions scored as 0, 1, 2, or 3, and provides a measure of depression. Total score is used: 0-5 mild, 6-10 moderate, 11-15 moderately severe and 16-20 severe depression. It is commonly used within the NHS (i.e. GP and IAPT services), and has good reliability and validity (Kroenke et al., 2001).

BOCS

The Brief Obsessive Compulsive Scale is a 15 item self-report version of the Yale Brown Obsessive Compulsive Scale (Y-BOCS, Bejerot et al., 2014). It is a checklist with a six item severity scale (scored as the mean on a 0-4 point scale) and provides a measure of obsessive-compulsive behaviour. It is able to distinguish obsessive-compulsive symptoms from other psychiatric conditions and compares well with the clinician-led Y-BOCS. A mean of greater than 1.5 on the severity scale with endorsement of two or more of the checklist items is suggestive of obsessive-compulsive issues at a clinical level.

Qualitative data

Qualitative data will be gathered via a semi-structure interview. Although, as Dickson-Swift et al. (2008) point out, there is a risk of preventing participants from telling their story if too much structure is used when researching sensitive subjects, a few guiding questions will be used. The questions will cover the individual's perceptions of:

- the nature and experience of their disordered eating/weight issue;
- their perception of the aetiology of these issues;
- diagnoses and, in particular, any diagnosis they have been given;

- the treatment they received (from medical professions);
- the treatment from society (including family, friends);
- how they feel treatment could be improved.

I will also, in reference to the standard questionnaires, establish if participants have awareness/prior experience of the questionnaires, how they feel they related to them and how useful these were to them in terms of increasing understanding and clarity around their own issues.

Data analysis

As the questionnaires chosen are used commonly in the health service by GPs, within IAPT services and in specialist Eating Disorder Units, these will provide a standard diagnostic profile of the individual. The qualitative data will provide the rich, lived experience data to compare with these diagnostic profiles. An examination across the weight spectrum will be conducted, using the diagnostic profiles and the lived experience data.

Thematic analysis (TA, Braun & Clarke, 2006) will be used due to its flexibility as well as its freedom from a specific theoretical framework. The intended readership for this research is not restricted to academics, as such TA is an appropriately accessible choice of analysis. In terms of the themes, I do not feel it is appropriate to try to specify what these may be at this point. A rich thematic description of the entire data set is my current aim but I remain open to the possibility that examination of one particular theme may be the more appropriate route to take.

I commit to taking an inductive approach to the analysis as this is the most open and least prescriptive option. There is still much to learn regarding disordered eating and I hope that adopting this open approach will be more productive in establishing greater understanding. There are several theoretical models around disordered eating (i.e. sociocultural, cognitive-interpersonal); the impact of cultural standards is a common theme but, as a health psychologist, I would hope to establish more encompassing, biopsychosocial understandings of the issue. What explains the variety of response to the cultural standard?

A critical realist ontology with a contextualist epistemology underpins the overall approach; the strong role of sociocultural 'standards' and perceived pressure and the varying response to these pressures is of particular interest. The generally held negative beliefs that individuals who are overweight are personally responsible and 'to blame' for their 'unhealthy state' is especially powerful and is reinforced in many ways within the media and our wider society. How do we view health within this context? What is a 'healthy body' and how should we assess this? With the choices made regarding data collection and analysis, I hope to be able to establish an understanding of disordered eating across the variety of weight presentations that takes into account the measurable and diagnostic approach but uses the individual perspective to establish suggestions as to how we might better improve our approach to supporting individuals with disordered eating. Currently, there is an emphasis on weight within disordered eating whilst simultaneously there is an acceptance that weight is not a strong indicator of health or 'ordered' eating. I hope to be able to get past this barrier to the underlying biopsychosocial issues while remaining sensitive to the individual experience.

I will also be using criteria to establish quality throughout my research. I am currently examining the eight "Big Tent" criteria (Tracy, 2010) as a framework for this. It takes an approach to quality that encompasses all forms of qualitative research and, with a strong emphasis on ethics, reflexivity and rigor, these criteria should prove useful from this point through to the completion of the research. However, I have recently been provided with some additional sources regarding quality and will be examining these also.

Ethical issues

This research seeks the perspectives and views of individuals with experience of disordered eating. This encompasses individuals who have been or are diagnosed with an eating disorder; individuals who have received treatment; individuals who have been refused treatment; individuals who have not had their challenges with disordered eating recognised; and individuals whose weight ranges through definitions of 'unhealthy' and 'healthy'. There are issues around recruiting vulnerable adults as research participants and it is important that I address these issues and ensure that the wellbeing of the participants is assured.

I used group supervision to discuss these issues and work out an approach that would ensure the wellbeing of participants will be assured: this will be covered in the final versions of the information sheet, the debrief and a contingency plan (which will be covered in the informed consent procedure).

I will give consideration to my own position within the research and how this will impact on the process. I will also be using supervision with my doctoral supervisor following data collection in order to manage potential risk to myself as researcher. It has been noted (Dickson-Swift, 2008) that potential risk to the researcher is not generally considered as part of risk management and ethical considerations when conducting sensitive research. With a background in clinical work, I am familiar with the impact that such work can have and will not neglect this aspect of the research process.

Progress and challenges

There have been four significant challenges so far:

- Rejection of initial proposal
- Delay in acceptance of revised proposal
- Communication delays with potential recruitment body
- Differing approach between working clinically and working as a researcher

Rejection of initial research proposal

I discussed the comments from the committee (see appendix 1) with my doctoral supervisor and we felt that the objections had, in part, arisen from my approach to describing the research; I work clinically with individuals who have been diagnosed with an eating disorder, individuals who are classified as overweight or obese who struggle with disordered eating, and also individuals who have a 'healthy BMI' who have struggled with disordered eating throughout their life. Supporting them with their challenges, validating their feelings and helping them cope with the stigma around these issues is a regular part of my work. As such, I feel I was not explicit around the issues of stigma and the potential to pathologise individuals. This was corrected in my amendments and response to this objection.

There were also some details that the committee picked up on that were helpful in refining the description and planning of the research, especially around clarifying the role of models, the issue of gender and also that of recruitment (see appendix 2).

Delay in acceptance of revised proposal

Without firm approval I was unable to progress in-line with the original timetable. Gaining approval for support with recruitment from Beat requires time for them to consider the research, and they required approvals from the university (research and ethical). Beat were willing to consider giving an agreement in principle if the research itself were approved (prior to ethical approval). As such, this aspect of the process stalled.

I submitted an amended and revised research proposal, addressing the objections from the committee, with a letter addressing each point (appendix 2). This was subsequently approved (appendix 3) enabling me to progress with communications with Beat. In real terms, this represented a setback of three months to my original timetable.

Communication delays with potential recruitment body

I resumed communication with Beat and received some helpful feedback on the approved research proposal along with some questions, which I subsequently addressed (see appendix 4). However, the timing for Beat was poor as they are in the midst of preparing and engaging with Eating Disorder Awareness Week 2017. Communications with Beat should become swifter from this point, however, this may result in a further delay to the original timetable.

Differing approach between working clinically and working as a researcher

Developing crisis and contingency plans are part of my clinical work and something that I am experienced in. However, approaching this as a researcher is different. I had reflected on the difference between a clinical and a research perspective following the original objections to my research proposal and then again, in more specific terms, following the questions from Beat. Using an opportunity for supervision with staff and colleagues, I was able to further clarify this difference and establish the need for a 'generic crisis and contingency plan' as part of the research. I have also examined guidance on conducting sensitive research (Dickson-Swift, 2008). I am currently in the process of writing the information, consent and debrief documents for the research.

8.7.1 Progression viva feedback

Graduate School

Fiona Marfleet

Doctorate in Health Psychology Researcher Department of Health and Social Sciences Faculty of Health and Applied Sciences

19 September 2017 Dear Fiona,

PROGRESSION EXAM (RD2)

Exploring the experiences of eating disordered and obese individuals: a mixed methods study

Following the Faculty Research Degrees Committee meeting I am pleased to notify you that the Committee approved a 'satisfactory/Pass' outcome of your Progression Exam. You may now proceed to the next stage of your registration.

Details of your next milestones are as follows:

Progress Review Stage 2-PR2a form and evidence due : 19/08/2018
Progress Review Stage 2-PRb form-Outcome due: 19/09/2018
Progress Review Stage 3-PR2a form and evidence due : 19/08/2019
Progress Review Stage 3-PRb form-Outcome due 19/09/2019
Final Submission and maximum end date: 26/01/2021

It is important to note that both you and your supervision team share a joint responsibility for the timely completion of each milestone and engagement with the administrative requirements as set out by the Graduate School. If you do not successfully complete any of the Progress Review points then your registration will be at risk, and you may be withdrawn from your research degree. You are advised to familiarise yourself with the contents of the Graduate School Handbook, Code of Practice and Academic Regulations, all of which can be found on the Graduate School webpages.

Please see below the examiners' comments:

"We spent much of our time together clarifying the research question, exploring the rationale underpinning it and fleshing out the methodology section. For example, discussing Fiona's plans for the sensitive recruitment of participants with disordered eating conditions/obesity via BEAT, whether she will recruit purposively (ie. considering factors such as gender and 'condition') and her use of 'mixed methodology'. In relation to the latter point, we explored the appropriateness and value of asking participants to complete quantitative measures, how quantitative data (from such a small sample) will be used to help answer the research question, how both quant and quali data will be integrated. Ethical dilemmas (e.g. how to manage patients requests for information related to their scores and safeguarding issues) were also discussed.

Fiona was able to defend her research with passion during the progression viva. She answered queries, responded to concerns and was very receptive to suggestions for improvements.

We are confident that the work presented is Fiona's own work. The progression report and viva together provided sufficient evidence of the appropriate scope of the research. We are happy that Fiona is working at doctoral level and is set to meet the UWE Doctoral Descriptors.

The following are recommendations aimed to develop the work and are not conditions of progression:

- PPI will be valuable in constructing a sensitive recruitment advert / interview schedule.
- Both examiners feel you would have sufficient data to inform your research question from the qualitative interviews alone. However, if you choose to identify this as a mixed methods study, clarify the purpose and justify the value of collecting quantitative data from such a small sample and provide detail regarding how you will integrate both quali and quanti data."

If you experience any issues affecting your ability to continue with your research as expected, please get in touch with the Graduate School as early as possible so that they can advise you accordingly.

Yours sincerely

Tim Moss

**Director of Research
Chair of the Faculty Research Degrees Committee Faculty of Health and Applied
Sciences**

*Cc Director of Studies (it is the responsibility of the DoS to ensure that this notification is
communicated to the whole team)*

8.8 Online questionnaire

8.8.1 Questionnaire

(This is a pdf export of the entire questionnaire, including all routes through the questionnaire. Where there were options, such as metric or imperial, participants were diverted to the relevant pages to enter their data)

Introduction

What's weight got to do with it?

An exploration of individuals' experiences of disordered eating across the weight spectrum

Weight is a personal issue, but one that forms the basis of judgements in our society, from friends and family, the general public and media, to healthcare providers/ professionals. Although, by itself, weight is not a strong indicator of health, Body Mass Index (BMI) plays a significant role in terms of gaining recognition for disordered eating and access to treatment. As disordered eating can occur across the entire weight spectrum, this focus on BMI is problematic.

This study, therefore, is open to individuals with experience of disordered eating, across the range of weight presentations, regardless of any diagnosis or lack of diagnosis for an eating disorder.

To continue with this study you will need to read this [information sheet](#) and complete the consent form. Participation in the study is entirely voluntary and you are not obliged to take part. Your responses will remain anonymous and confidential and cannot influence decisions around provision of treatment by your health care professionals.

Please note: You can exit the study by closing the window/tab it appears in. It will automatically save your answers. You can re-enter the survey by using the link. Alternatively, you can leave a browser window with the survey open while you are taking part in the study. The software places a cookie on your browser to track your progress so you need to use the same device throughout the study.

If you have any questions about the research, before, during or after, please contact me at [REDACTED]

Your participant ID is: \${e:// Field/ Participant%20ID}

If you decide to take part in the study, please take a note of this ID. If you wish to withdraw from the study at a later date, send me an email with 'Withdrawal' as the subject and the ID number in the body of the email.

If you feel you need support, please contact your GP or use one of these [support lines](#) and information.

Many thanks for your interest!

Consent form

Consent form

-
- I confirm that I have read and understood the participant information sheet
 - I understand that my participation in this study is entirely voluntary and that I have the right to withdraw from the study at any point prior to completion of the data analysis (24th November 2017)
 - I understand that all data collected will be anonymised, treated as confidential, used for research purposes only and that the final report may be published in relevant scientific journals
 - I understand that any identifying data, including personal contact details (for the purposes of the interview) will be destroyed once the data collection is completed
 - I confirm that I have experience of disordered eating
 - I understand that, should I wish to withdraw, I need to send an email to the researcher, with my response ID, with the email subject 'Withdrawal'
 - I confirm that I am aged 18 years or over
 -

I confirm that I am a UK resident

Don't forget to take a note of your participant ID number.
You can use the back button below to navigate to previous screens.
Your participant ID number appears on the first screen.

Demographics

Age

Gender

- Male
- Female
- Prefer not to answer
- Prefer to self-describe

This research questions the role of weight in determining disordered eating and health, however, in order to conduct the research I need to ask about weight.
You can do this in metric or imperial.

- Metric
- Imperial

Please enter your current weight in pounds

Please enter your height in feet and inches

Feet

Inches

Please enter your weight in kilograms

Please enter your height in centimetres

I will be randomly selecting individuals for participation in the interview component of the study. In order to do this I will need a current email address. This information will be destroyed following completion of the study (or following provision of a summary of the research, if required - option provided later).

Please remember, you may withdraw from the study at any point up to completion of the data analysis (24th November 2017)

Diagnosis

Diagnosis

Have you received a/any diagnoses regarding your mental health?

- Yes
 No

What diagnoses have you received?

Please select all diagnoses you have received either now or in the past.

- Anorexia nervosa
 Bulimia nervosa
 Binge Eating Disorder
 Eating Disorder Not Otherwise Specified
 Avoidant and Restrictive Food Intake Disorder
 Depression
 Anxiety
 Obsessive Compulsive Disorder
 Other (please provide detail in the text box)

Which diagnoses, if any, do you feel fit with your experiences?

Please select all diagnoses you feel are appropriate.

- Anorexia Nervosa
 Bulimia Nervosa
 Binge Eating Disorder
 Eating Disorder Not Otherwise Specified
 Avoidant and Restrictive Food Intake Disorder
 Depression
 Anxiety
 Obsessive Compulsive Disorder

Other (please provide detail in the text box)

Treatment

Treatment

Have you received any treatment for your disordered eating or any other mental health condition?

Yes

No

What treatment(s) have you received?

Are there any treatments for disordered eating or any other mental health condition that you would have liked to receive/would like to receive?

Block 6

If you would like to check any of your responses or remind yourself of your participant number, please use the back button below to navigate through the previous screens.

Thanks!

Thank you for taking the time to complete the questionnaire. I will contact participants that have been randomly selected to take part in the interview element of the research by 29th September 2017.

The questions in this study are not intended to cause you any distress, however, if you are left with any difficult feelings following completion of this questionnaire, please consider contacting one of the following sources of support:

Beat

Helpline: 08088010677 (3-10pm all year round)

Youthline: 08088010711 (3-10pm all year round)

www.b-eat.co.uk/support-services (includes email contact, message boards, online support)

groups and peer support groups)

Samaritans

Helpline: 08457909090
Email: jo@samaritans.org
www.samaritans.org.uk
Service available 24 hours a day, all year round

Mind

Infoline: 03001233393 or text 86463 (information on types of mental health problem, where to get help, medication and alternative treatments and advocacy)
Lines open 9am – 6pm Monday to Friday (except bank holidays)
Email: info@mind.org.uk
www.mind.org.uk/information-support/helplines/

Sane

Helpline: 03003047000
Service available 4:30 pm to 10:30 pm every evening
www.sane.org.uk/what_we_do/support/

Understanding your eating (information, online and face-to-face courses available)
www.understandingyoureating.co.uk

8.8.2 Information sheet

What's weight got to do with it?

An exploration of individuals' experiences of disordered eating across the weight spectrum

Thank you for your interest in the study.

This document gives you important information about the study such as what is involved and who can take part.

This will enable you to make a decision about whether you want to take part. Participation in the study is entirely voluntary.

Reasons for the research

Weight and disordered eating are associated, but there are common assumptions made regarding weight presentation and disordered eating that would benefit from further examination.

What do you mean by 'disordered eating'?

I am using the term 'disordered eating' to refer to behaviours (including restrictive practices, bingeing, purging, missing meals, using frequent meal substitution, excessive exercise used for weight control and other extreme weight control practices). Any behaviours that are seen to disturb a healthy eating pattern may be considered as 'disordered'.

This is distinct from the term 'eating disorder', which relates to specific diagnoses and specific diagnostic criteria.

People diagnosed with an eating disorder will have disordered eating. Some people without an eating disorder diagnosis may also have disordered eating.

For more information about disordered eating and eating disorders visit the Beat website (<https://www.b-eat.co.uk/about-eating-disorders/types-of-eating-disorder>).

Why me?

This study is open to individuals with experience of disordered eating.

I am keen to hear from people across the weight spectrum as disordered eating is often not recognised in people who are considered to be at a 'healthy weight' or people who are considered to be 'overweight'.

You don't need to have a diagnosis of an eating disorder – it's about your experience of disordered eating.

I am seeking both female and male participants for this research but participation is restricted to individuals aged 18 or over. You will also need to be an English-speaking UK resident (regrettably I cannot afford translators).

Right to withdraw

You are free to change your mind about participating in the research at any point prior to completion of the data analysis. Your anonymity is assured. If you wish to withdraw, please send me an email, with the subject 'Withdraw', and your participant ID number in the body of the email. Your participant ID number is on the first page of the study (where you found the link to this document).

What do I have to do?

The research involves two aspects:

1. Questionnaire (online)
2. Interview (either online via Skype, phone or face-to-face depending on geographical location and preference).

The questionnaire asks some basic demographic questions (i.e. age, gender, height and weight), and asks about diagnoses and treatments. The healthcare system uses a diagnostic process, and associates various issues with disordered eating (depression, anxiety, obsessive-compulsive behaviours); the questionnaire includes questions regarding these diagnoses (in addition to eating disorder diagnoses) and is intended to gather the current 'healthcare perspective'.

The interview will be about your own perspective.

The questionnaire and the interview will also be an opportunity for you to reflect on your experiences. Although it is not intended to cause any upset, sometimes talking about these things can bring up some difficult feelings. I have included information regarding sources of support, should you find the questionnaire or parts of the interview difficult in any way. Prior to interview, I will also ask for a contact number for someone you find supportive; I would only contact that person should you require support during or immediately on completion of the interview. This is to ensure that you are not left alone with any difficult feelings. This contact information will be destroyed after the interview.

How do I get involved?

- Read through the rest of this document.
- Read through the consent form and provide your consent. If you are using a mobile phone, this will involve clicking on each line to indicate your acceptance; on other devices, you will need to click in the tick boxes provided.
- Proceed to the questionnaire.

This is a study which explores your experiences in-depth so I will only require about 12 people to take part in the interview aspect of the research.

As I am interested in hearing from individuals across the spectrum of weight presentations, the demographic questions will include a question about weight. This is to enable me to include people across the weight spectrum.

The questionnaire will close at midnight on the 29th September 2017. Participants selected for interview will then be contacted.

Confidentiality

In order to take part in the interview, I will need your contact details in order to arrange the interview. Once the interviews are completed, all identifying references and contact details will be destroyed and your data will remain anonymous. All data gathered from individuals who complete the questionnaires, but do not take part in the interviews, will also remain confidential.

What happens with the findings from the research?

A summary of the outcomes of the research can be sent to you on request; this information will be for your own personal reference and is not to be reproduced or distributed without prior consent.

The final report may also appear in relevant psychological and health related journals.

Who is running the research?

Myself, as a doctoral student (Health Psychology) at the University of the West of England (UWE), under the supervision of Dr Rachel Gillibrand (also UWE). The research has been reviewed and cleared by the ethics committee at the university and is run in accordance with the ethical guidelines of the British Psychological Society.

Contacts

If you have any questions about the conduct of the research please contact:
Fiona Marfleet at the University of the West of England, [REDACTED]; or
my supervisor Dr Rachel Gillibrand, also at the University of the West of England,
[REDACTED]).

If you decide to take part in this study, you will now need to complete the consent form.

Participation in the study is entirely voluntary and you are not obliged to take part. Your responses will remain anonymous and confidential and cannot influence decisions around provision of treatment by your health care professionals.

Thanks again for your interest!

8.8.3 Support lines

Support lines and useful contacts:

Beat

Helpline: 08088010677 (3-10pm all year round)

Youthline: 08088010711 (3-10pm all year round)

www.b-eat.co.uk/support-services (includes email contact, message boards, online support groups and peer support groups)

Samaritans

Helpline: 08457909090

Email: jo@samaritans.org

www.samaritans.org.uk

Service available 24 hours a day, all year round

Mind

Infoline: 03001233393 or text 86463 (information on types of mental health problem, where to get help, medication and alternative treatments and advocacy)

Lines open 9am – 6pm Monday to Friday (except bank holidays)

Email: info@mind.org.uk

www.mind.org.uk/information-support/helplines/

Sane

Helpline: 03003047000

Service available 4:30 pm to 10:30 pm every evening

www.sane.org.uk/what_we_do/support/

Understanding your eating (information, online and face-to-face courses available)

www.understandingyoureating.co.uk

8.8.4 Debrief

Thank you for taking the time to complete the questionnaire. I will contact participants that have been randomly selected to take part in the interview element of the research by 29th September 2017.

The questions in this study are not intended to cause you any distress, however, if you are left with any difficult feelings following completion of this questionnaire, please consider contacting one of the following sources of support:

Beat

Helpline: 08088010677 (3-10pm all year round)

Youthline: 08088010711 (3-10pm all year round)

www.b-eat.co.uk/support-services (includes email contact, message boards, online support groups and peer support groups)

Samaritans

Helpline: 08457909090

Email: jo@samaritans.org

www.samaritans.org.uk

Service available 24 hours a day, all year round

Mind

Infoline: 03001233393 or text 86463 (information on types of mental health problem, where to get help, medication and alternative treatments and advocacy)

Lines open 9am – 6pm Monday to Friday (except bank holidays)

Email: info@mind.org.uk

www.mind.org.uk/information-support/helplines/

Sane

Helpline: 03003047000

Service available 4:30 pm to 10:30 pm every evening

www.sane.org.uk/what_we_do/support/

Understanding your eating (information, online and face-to-face courses available)

www.understandingyoureating.co.uk

8.8.5 Twitter promotion

“Struggled with #disordered #eating? Seeking participants for a study on DE experiences across the #weight spectrum. <link to online survey>”

8.8.6 Facebook promotion

“For my thesis I am conducting research into experiences of disordered eating across the weight spectrum. I’ve heard so many stories of a lack of recognition for disordered eating at ‘healthy’ and ‘overweight’ statuses that I thought it required further enquiry. So I am looking for people to take part. If you, or anyone you know has experience of disordered eating, whether you’ve received a diagnosis or not and regardless of your weight, could you please complete this questionnaire? It’s a small study and I will need a few people to interview too. Thank you so much! Here is the link: <link>”

8.8.7 Email to support groups

Hi,

I wonder if you could help me?

I am a doctoral researcher at the University of the West of England, Bristol, in my final year and am conducting research on experiences of disordered eating across the weight spectrum. I have worked with people diagnosed with eating disorders and also people with disordered eating who have not had their distress recognised - it seems that weight can act as a barrier to having this distress recognised. My research aims to explore experiences of disordered eating across the weight spectrum.

It is a small-scale study and I only require 12 people in total but will need to select people to represent a range of different weight presentations to achieve the aims of the research. The research involves a very short questionnaire and then an interview (phone or Skype at the participants convenience). The study has been passed by the ethics committee and also conforms to the ethical guidelines set out by the British Psychological Society. Anonymity and confidentiality are assured.

I am currently recruiting people to take part and wondered if you would be able to pass the link on to potential participants?

https://bristol.az1.qualtrics.com/jfe/form/SV_3qlzRhIGFwF8EGF

I would be grateful of any help you can offer with this. Please feel free to contact me if you have any questions.

Many thanks

Fiona Marfleet

Trainee Health Psychologist: T [REDACTED]

8.8.8 Promotion on B-eat Website, Facebook page

Fiona would like to interview over 18s with experience of disordered eating or an eating disorder who have received some form of treatment. She would like to ask participants about their perceptions of their own disordered eating, their views on what may have caused it, how they have been treated socially (by family, friends etc.) and their experiences of treatment. To find out more about the study and how you can take part please visit the page for the study on our website - <https://www.b-eat.co.uk/research/participate-in-research/11541-experiences-of-disordered-eating-across-the-weight-spectrum>

8.9 Interview schedule/framework and materials

8.9.1 Email sent to participants pre-interview

Hi,

Recently you took part in the online questionnaire element of my research into experiences of disordered eating across the weight spectrum, kindly promoted by Beat.

I am contacting you now to ask if you would be willing to take part in the interview aspect of this research.

Before agreeing to this I would like to go through what you can expect in the interview and confirm your consent to take part.

I have attached the information sheet from the questionnaire as a reminder of the general background and reasons for the research and also to help you make a decision on whether to agree to take part in the interview. There is no obligation to do so and you may also change your mind during or any time after the interview, up until completion of the data analysis (24/11/17).

The interview would take approximately an hour and be conducted over the phone.

The focus is on your perspective and will explore your experience of disordered eating, diagnosis and different treatments as well as your experiences with health care professionals, family, friends and in society in general. I will also be asking your views on the origins of the disordered eating and any thoughts you have around how we improve our understanding and approach to disordered eating in health care and in society.

Although the interview is not intended to cause any upset, sometimes talking about these things can bring up some difficult feelings. I have attached information regarding sources of support, should you find parts of the interview difficult in any way. As specified in the information preceding the online questionnaire, I am also asking for a contact number for someone you find supportive; I would only contact that person should you require support during or immediately on completion of the interview. This is to ensure that you are not left alone with any difficult feelings. This contact information will be destroyed after the interview.

As relying on memory of an interview is unwise, I am also seeking your consent to record (voice only). This recording will be destroyed following completion of the analysis phase of the research (24/11/17).

Anonymity and confidentiality are assured. The data will be kept secure on a password-protected computer and will be used solely for this research; data will not be shared with any third parties.

I have included the consent form statements below:

- I confirm that I have read and understood the participant information sheet

- I understand that my participation in this study is entirely voluntary and that I have the right to withdraw from the study at any point prior to completion of the data analysis (24th November 2017)
- I understand that all data collected will be anonymised, treated as confidential, used for research purposes only and that the final report may be published in relevant scientific journals
- I understand that any identifying data, including personal contact details (for the purposes of the interview) will be destroyed once the data collection is completed
- I confirm that I have experience of disordered eating
- I understand that, should I wish to withdraw, I need to send an email to the researcher, with my response ID, with the email subject 'Withdrawal'
- I confirm that I am aged 18 years or over
- I confirm that I am a UK resident

If you wish to take part in the interview, please reply to this email by Friday 15th October and we will proceed to arrange a time that is convenient.

If you do not wish to take part please reply to this email with the subject 'declined'.

Thank you for taking part in the research so far.

Best regards

Fiona Marfleet

Follow-up emails were used as required to ask for the additional contact number.

8.9.2 Interview verbal consent check

- Introduce and thank participant for their time. Check that this time is still convenient
- Check that the participant is clear about the research, that there are no misunderstandings (refer to information sheet) and that they are happy for the interview to be recording for transcription purposes (with recordings being deleted following completion of the research)
- Remind participant of their rights to withdraw, the time limit for withdrawing data, who to contact if they have concerns about the research
- Discuss the additional supportive person contact information – check that they are happy for me to use that should the need
- Reassure that they can stop the interview at any point
- Collect ethnic demographic

8.9.3 Interview schedule

Start point: This interview is about YOUR perceptions and perspectives on your experiences. Can you start by telling me about your experience of disordered eating and weight issues? You can approach this anyway you like.

Framework

- Nature of the disordered eating – behaviours
- Experience – trajectory of the disordered eating including weight fluctuations
- Views on aetiology
- Views on Exacerbating factors
- Interactions with healthcare professionals including diagnostic experiences
- Support – sought or provided, forms of
- Experiences within the family
- Experiences with friends
- Experiences at school/work
- Views on potential improvements

During interview: constant vigilance for signs of distress. Pause and check before proceeding if signs of distress are apparent.

Following interview: Thank participant for taking part. Remind them that they can contact me following if they have any concerns etc. Ask if they would like a summary of the research outcomes and check they are happy for me to keep their email contact details for that purpose. Reassure them that all data is confidential, no identifying detail will be included in the final paper submitted for publishing.

8.9.4 Post-interview email

Hi <name>

I would like to thank you once again for taking part in this research. The participation of individuals such as yourself, allows researchers to improve understanding and influence positive change in both practice and policy. I am grateful for your time and your willingness to share your experiences, perceptions and perspectives.

I hope you feel that taking part has been beneficial but if you have any queries or concerns you can contact myself (redacted) or my doctoral supervisor, Dr Rachel Gillibrand (redacted).

I will, as requested send a summary of the research outcomes, hopefully around the middle of next year. I also aim to publish the final research – if you wish to be notified of this, please email me. The link between weight and health, both mental and physical, is not straight forward - approaches to disordered eating vary across the country and accessing support can be difficult. This is further complicated by the role of weight within diagnostic process and treatment guidelines, the stigma across all aspects of life and societal ideas regarding appearance. You may be interested in the Endangered Bodies local-global initiative that is promoting positive change regarding body image (www.endangeredbodies.org). In the UK there is also the 'Be Real' campaign that is campaigning to change attitudes to body image (www.berealcampaign.co.uk). There is also a report from the UK government about body image from the body confidence campaign that you may find interesting (www.gov.uk/government/uploads/system/uploads/attachment_data_file/417186/Body_confidence_progress_report_2015.pdf).

Thank you again for taking part in the research.

Best regards

Fiona Marfleet

8.10 Descriptive analysis of each weight category

Frequency distributions and descriptive data

8.10.1 Weight categories: 'underweight'

N		73
Age	Range	18-55
	Mode	22
	Median	24
	Mean	26.2
BMI	Range	12.5-18.4
	Mode	18.1
	Median	17.3
	Mean	16.9
Diagnoses	No diagnosis	4
	ED diagnosis only	10
	ED + other diagnoses	58
	Other diagnoses only	1
Treatment	No treatment	1
	One treatment only	5
	Multiple treatments	67

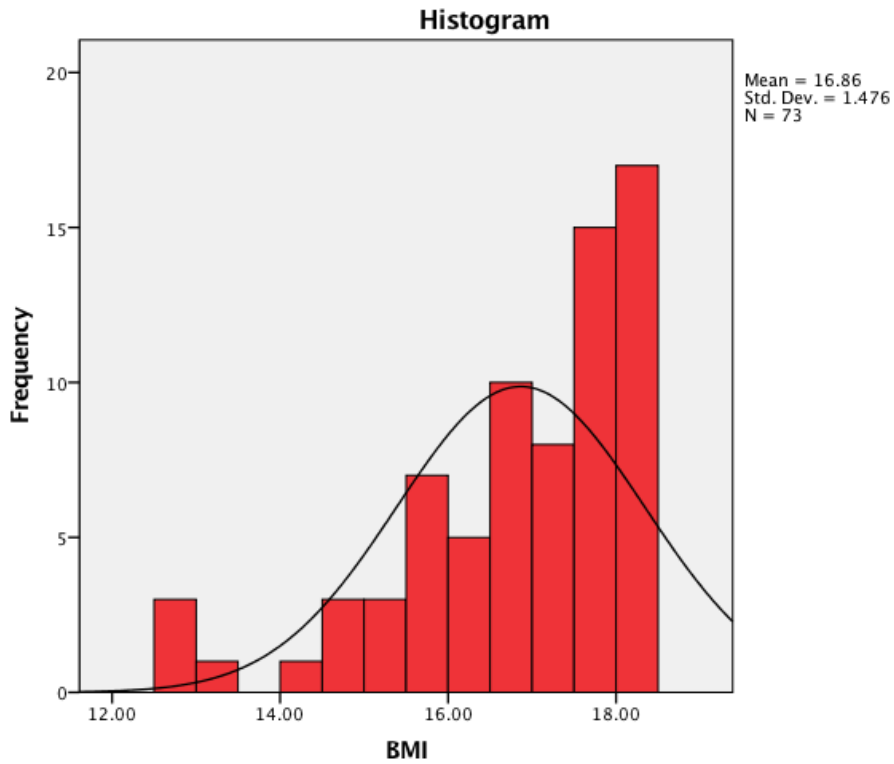


Figure 8: BMI spread/frequencies within the 'underweight' category

8.10.2 Weight categories: Healthy weight

Table 9		
<i>Summary of healthy weight category</i>		
N		169
Age	Range	18-52
	Mode	20
	Median	25
	Mean	27
BMI	Range	18.5-24.9
	Mode	19.0
	Median	20.1
	Mean	21.1
Diagnoses	No diagnosis	13
	ED diagnosis only	25
	ED + other diagnoses	123
	Other diagnoses only	8
Treatment	No treatment	11
	One treatment only	26
	Multiple treatments	124

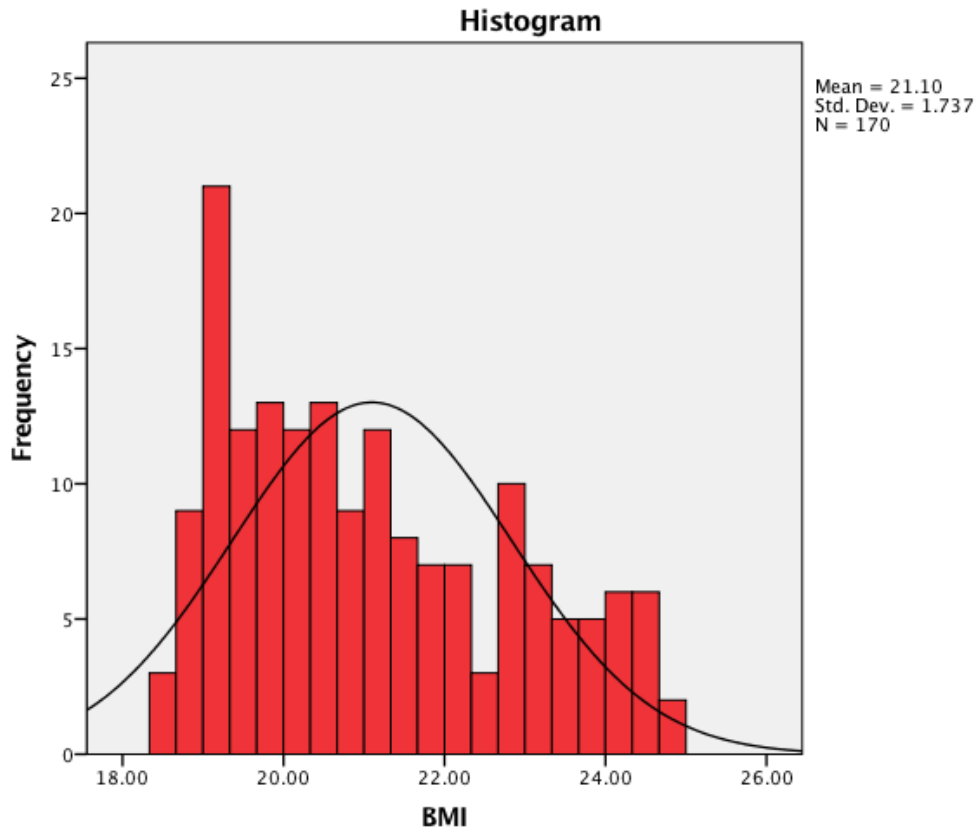


Figure 9: BMI spread/frequencies within the healthy weight category

8.10.3 Weight categories: 'overweight'

Table 10		
<i>Summary of 'overweight' category</i>		
N		28
Age	Range	18-44
	Mode	19
	Median	19
	Mean	28.9
BMI	Range	25-29.7
	Mode	25.4
	Median	26.3
	Mean	26.5
Diagnoses	No diagnosis	4
	ED diagnosis only	3
	ED + other diagnoses	19
	Other diagnoses only	2
Treatment	No treatment	4
	One treatment only	1
	Multiple treatments	23

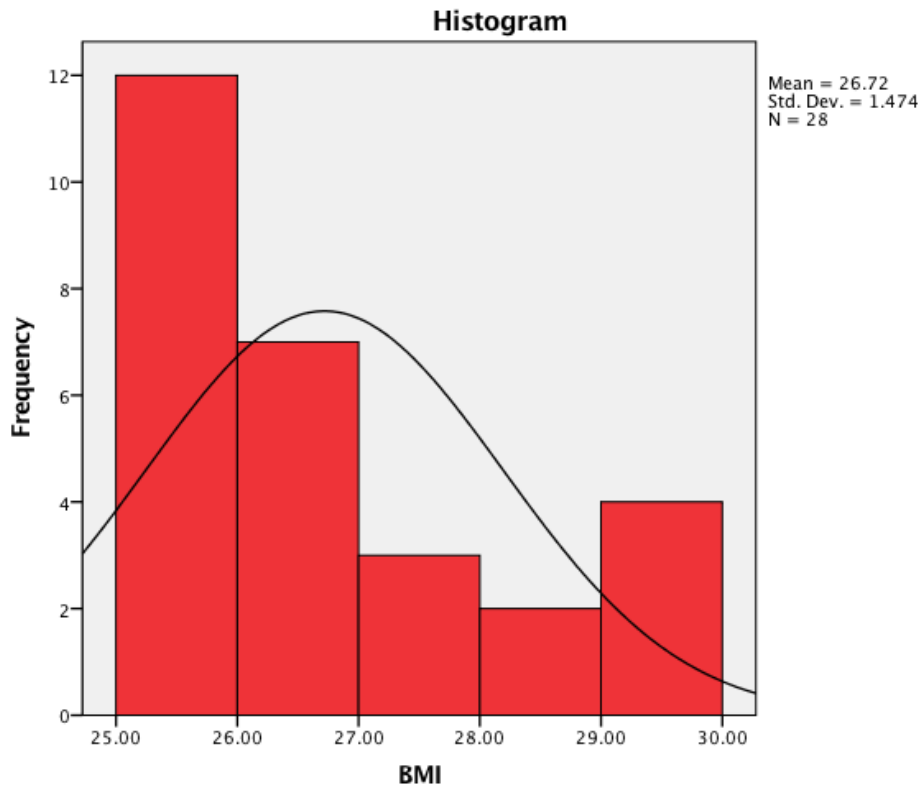


Figure 10: BMI spread/frequencies within the 'overweight' category

8.10.4 Weight categories: Obese

Table 11		
<i>Summary of 'obese' weight category</i>		
N		39
Age	Range	18-49
	Mode	37
	Median	31
	Mean	31
BMI	Range	30-57.7
	Mode	37.1
	Median	36.3
	Mean	37.8
Diagnoses	No diagnosis	7
	ED diagnosis only	3
	ED + other diagnoses	22
	Other diagnoses only	7
Treatment	No treatment	5
	One treatment only	8
	Multiple treatments	26

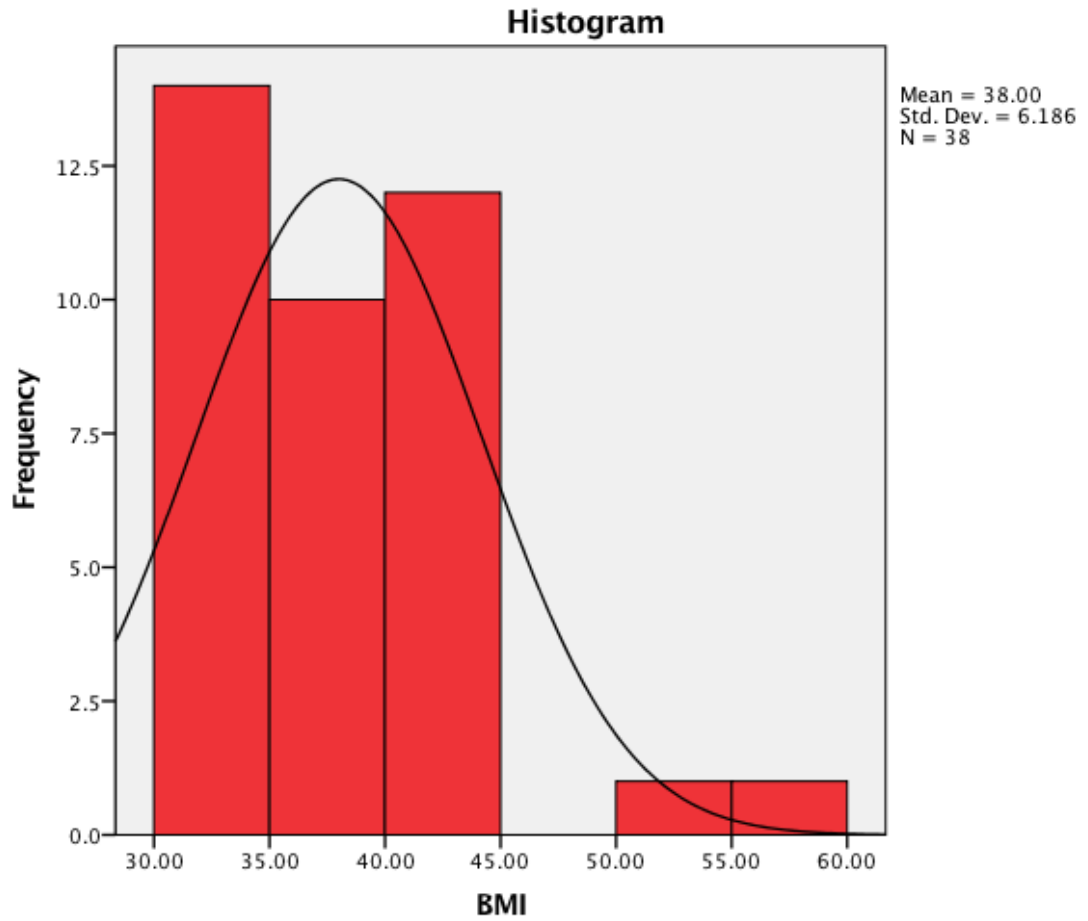


Figure 11: BMI spread/frequencies within the 'obese' weight category

Table 12			
<i>Summary of categories of obesity</i>			
Obesity I	N		15
	Age	Range	18-46
		Mode	25
		Median	25
		Mean	29
	BMI	Range	30.0-34.7
		Mode	
		Median	32.5
		Mean	32.3
	Diagnoses	No diagnosis	2
		ED diagnosis only	1
		ED + other diagnoses	10
		Other diagnoses only	2
Treatment	No treatment	2	
	One treatment only	4	
	Multiple treatments	9	
Obesity II	N		10
	Age	Range	19-41

		Mode	31
		Median	30.5
		Mean	29.9
	BMI	Range	35.3-38.5
		Mode	37.1
		Median	36.7
		Mean	36.8
	Diagnoses	No diagnosis	3
		ED diagnosis only	1
		ED + other diagnoses	5
		Other diagnoses only	1
	Treatment	No treatment	1
		One treatment only	1
Multiple treatments		8	
Obesity III	N		14
	Age	Range	21-49
		Mode	49
		Median	33
		Mean	34
	BMI	Range	41.0-57.7
		Mode	41
		Median	42.6
		Mean	44.4
	Diagnoses	No diagnosis	2
		ED diagnosis only	1
		ED + other diagnoses	7
		Other diagnoses only	4
	Treatment	No treatment	2
		One treatment only	4
		Multiple treatments	8

8.11 Researcher's position

I take a critical health psychology perspective in general terms but specifically in terms of weight and health, and this perspective derives from the experiences of working across a variety of settings as well as my own reading/studies and my personal experiences.

Acknowledging my own privilege, as well as my own challenges, I realise I was fortunate to have been raised in a house where diets and dieting were not discussed or practiced. My body-image was not questioned or criticised. Establishing my own identity across my formative years did involve much questioning though, and I was encouraged to take a critical stance to many aspects of everyday living. Health was something I took for granted however, until my own health came into question, causing me to turn my critical stance towards health issues in general.

Working with individuals with ED diagnoses, I became aware of the extreme distress, anxiety and pain that underpinned their daily existence but was also aware of the impact of multiple contexts and the complexity of the individuals. Across this period of working, I read more about the various types of ED. This was around the time that the DSM-5 was published, with the inclusion of BED as a separate diagnosis for the first time. Although most of the people I had worked with had had diagnoses of AN or BN or EDNOS, I had seen only a limited range of weight presentations, some 'underweight', some 'healthy' weight. With BED, weight presentations tend to be more within the 'overweight' or 'obese' BMI categories. Reading more around BN, I realised that the weight presentation for this diagnosis varied, with some individuals, falling within the 'overweight' and the 'obese' BMI ranges. I realised that I had an image of an individual with an ED as being 'underweight', as many people do without experience regarding EDs, and this assumption was fundamentally flawed. I began to wonder how widely these kinds of assumptions were held and what

impact this might have regarding care; I had seen the kind of distress and challenges that EDs brought – how was this handled when someone was not presenting with the ‘underweight’ body-image? Examining more closely the issues facing individuals living with obesity, the issue of weight stigma jumped out of the literature. The media coverage of ‘the obesity epidemic’ displayed a range of assumptions being made around individuals who were ‘overweight’ or living with obesity and these assumptions were almost entirely negative.

The Foresight report (2007) made it clear that the causes of obesity were multiple and complex, with the majority of causal factors lying beyond the reach or control of the individual yet there was a rhetoric of blame and personal responsibility.

From working in the field with individuals with ED diagnoses and with individuals living with obesity, it was clear that gaining validation and treatment were, in many instances, ‘gate-kept’ by weight: individuals were denied treatment for EDs because they weren’t sufficiently ‘underweight’ (McCubbin, 2016); there are BMI criteria for referrals to specialist weight management services, yet the psychological impact of DE is ‘weight-blind’, and malnutrition has serious impacts on both physical and mental health in the short, medium and longer term.

8.12 Complete list of treatments

<p>Teams</p> <ul style="list-style-type: none"> • Crisis_Team • Outreach_Team • CommunityMentalHealth_Adult • ED_Centre • CAMHS 	<p>Hospital</p> <ul style="list-style-type: none"> • Outpatient • Inpatient • Day_patient
<p>Approaches/therapies/treatments</p> <ul style="list-style-type: none"> • MBT • DBT • CBT • CBT_ED • CBT_OCD • Mindfulness • Therapy_Unspecified • Therapy_CAT • Therapy_ACT • Therapy_EMDR • Therapy_NLP • Therapy_Psychotherapy • Therapy_Group • Therapy_Existential • Therapy_Family • Therapy_Hypno • Therapy_Private • Therapy_Art • Therapy_EFT • Therapy_Play • Therapy_Drama • Body_Image_Work • Counselling_Generic • ECT • CRT_treatment • Maudsley_Clinic • ReFeeding • Acupuncture 	<p>Healthcare professionals</p> <ul style="list-style-type: none"> • Dietitian • Nutritionist • Psychologist_General • Psychiatrist • ASD_specialist • OT • GP_Care • Life_Coaching
	<p>Medications</p> <ul style="list-style-type: none"> • Unspecified • AntiDepressants • Anxiety • Fluoxetine • Citalopram • Sertraline • Venlafaxine • Mirtazapine • BetaBlockers • Sibutramine_Reductil
	<p>Peer_Support_Groups</p>
<p>Treatment_Unspecified</p>	

(This treatment list was generated from a free-entry question on the online questionnaire)

Are psychological interventions effective in reducing weight long-term, in an obese population (BMI > 30), compared to lifestyle interventions (diet and exercise)?: A systematic review

Abstract

Context: Obesity is a health issue impacting individuals and communities on a national and global level. The increased health risks that accompany obesity (i.e. cardiovascular disease (CVD), type II diabetes, certain cancers) increase healthcare costs, impact productivity, and place additional burdens on the individual; there are many challenges to living with obesity, including the pressures arising from the stigma attached to being overweight. There are two distinct areas of focus: prevention and treatment. Regarding treatment, the commonly promoted 'diet and exercise' approaches do not lead to sustained weight-loss in the majority of cases; alternative and additional approaches need to be sought. It has been noted that there are often associated and underlying psychological factors to obesity, which contribute to behaviour change or the lack thereof.

Objective: To assess the efficacy of psychological approaches regarding long term weight loss (>12 months) in an adult obese population as compared to standard diet and exercise approaches. Studies were considered from 2000 onwards that were published in English. Data sources: Databases that included psychological approaches to health behaviours were used (EMBASE, PsycINFO, PsycARTICLES, PubMed and Cochrane).

Study selection: Studies that compared psychological approaches with diet and exercise or compared psychological approaches combined with diet and exercise, against diet and exercise approaches were included. Only studies with adult participants were included and those that assess weight loss at 12 months or more after engagement with treatment. Studies were assessed using the Effective Public Health Practice Project (EPHPP) quality assessment tool. Only studies rated as strong or moderate were included in the analysis.

Data extraction/synthesis: The following data were extracted for analysis: nature of the psychological intervention; duration of the intervention; number of participants included; timing of the follow-ups; outcome of the weight loss compared with the control group; and other significant positive health outcomes. A narrative synthesis was conducted due to the variety of psychological interventions used.

Conclusions: The evidence suggests that the prospect of long term weight loss in an obese adult population is significantly improved by the addition of psychological interventions, with face-to-face support, to the standard 'lifestyle' approaches of diet and exercise. The psychological intervention needs to be suited to the individual; the concepts of treatment motivation and therapeutic alliance are of particular importance and require further investigation. When using psychological interventions, individuals need to be motivated to work psychologically. Studies with strict randomisation showed higher attrition rates than studies where participants self-selected into the treatment arm. Analysis of withdrawals and drop-outs suggested that those individuals did not favour the psychological approach on offer. Where the difference between instructors was analysed, different instructor effects were apparent, indicating that the conduct of the instructor and potentially the relationship between the instructor and the participants is of importance regarding outcome. This requires further research. It is recommended that policy-makers within health services and guidance bodies such as NICE (National Institute

for Clinical Excellence) review psychological interventions prior to the provision of the next update of guidance regarding treatment options for the adult obese population.

Introduction

Rationale

The impact of obesity: Obesity is a problem on an individual, national and global level with serious health risks attached to the condition. The World Health Organisation (WHO, 2015) underline the link between a body mass index (BMI) above the 'healthy' level of 18-25 and non-communicable diseases. They state that a raised BMI increases the risks of cardiovascular diseases (mainly heart disease and strokes; the leading cause of death globally in 2012), diabetes, musculoskeletal disorders (especially osteoarthritis) and some cancers (endometrial, breast and colon particularly). These risks are also noted by the Department of Health ('Healthy Lives Healthy People', 2011) and The Blackfriars Consensus (Public Health England and the UK Health Forum, 2014), who refer to obesity as one of a number of vascular risks for dementia.

At governmental level in the UK, the financial costs of obesity are clear. McKinsey and Co (Dobbs et al., 2014) calculate the annual costs to the NHS to be in the region of £6bn. Their data indicate that obesity is second only to smoking regarding human-generated impact on the UK, affecting productivity at work and business costs, healthcare costs and costs of prevention programmes. Obesity differs from many other serious health issues though.

The nature of obesity: In order to successfully address any health problem, a clear understanding is important. This 'clear understanding' is not present regarding obesity. Ezzat (in Shea et al., 2012) states that "...knowledge of the genesis and progression of obesity remains rudimentary." Sharma (in Shea et al., 2012), posits that obesity is due to "...complex factors..." and includes "...high stress levels and increased prevalence of mental health problems.", in a list of the key drivers (also including availability of energy-dense foods and our sedentary lifestyles). Sharma points out that the body protects its weight, so weight loss can promote weight regain. Despres (in Shea et al., 2012) also talks about the complex range of factors influencing weight gain and obesity, highlighting the sociocultural components. He does not feel that we are doing enough to target this area in terms of education and prevention. He also stresses the importance of not viewing obese individuals as one homogenous group; the underlying causes differ, which suggests a variety of treatment options. He believes it is important to improve the general health profile of individuals rather than focusing purely on weight loss. The UK government's Foresight report (Butland et al., 2007) also stresses the variety of factors involved and the need for a comprehensive approach. The WHO state that "Curbing the global obesity epidemic requires a population-based multi-sectoral, multi-disciplinary, and culturally relevant approach" (WHO, 2015) and further suggest that, in order for an individual to take the necessary responsibility to facilitate weight loss and health maintenance, supportive environments and communities are vital.

There is also the additional problem of stigmatization. Professor Rubino (in Chipman 2015) says "There is some sort of social and cultural stigma that makes obesity different from any other disease we know." There is cultural emphasis on weight loss and appearing visibly smaller, and fears of public humiliation can act as a barrier to participation in health promoting activities. As Chipman (2015) points out, prevention programmes "... can increase the stigmatisation of obese and overweight people; in turn, stigmatisation can contribute to restricted access to treatment for severely obese individuals." Obesity represents a serious problem and a serious challenge to the individual, those trying to understand the condition fully and those trying to prevent and

treat the condition. Taking a 'chronic disease' approach, multi-component and multi-disciplinary, is suggested (Shea et al., 2012).

Current approaches: Chipman (2015, ed. Koehring) state that there are currently no European countries with a comprehensive understanding and approach to obesity. Admitting that our knowledge is limited is a first step towards developing a comprehensive approach, according to Professor Francesco Rubino, chair of metabolic and bariatric surgery at King's College London (Chipman 2015). The report, *Confronting Obesity in Europe: Taking Action to Confront the Default Setting*, points to the existence of two distinct groups: those requiring preventative measures, not yet overweight or obese, and those that are already obese, for whom the currently used lifestyle and behavioural approaches are largely ineffective.

In the UK, treatment is based around the NICE guidelines (National Institute for Clinical Excellence, 2015). NICE provide a stepped approach to treating overweight and obesity, with different levels of intervention depending on risk. At step 1, general advice on healthy weight and lifestyle; step 2, diet and physical exercise; step 3, diet and physical exercise – consider drugs; and step 4, diet and physical exercise – consider drugs – consider surgery. Patients can be referred by their GP for 12 weeks free membership of a weight loss group and/or 12 weeks free membership of a local gym/leisure centre, in line with steps 1 and 2. There are serious questions over the long-term efficacy of such referrals though. Buckworth and Dishman (2002) (in Annesi and Walker) suggest that establishing an exercise habit can take considerable time and the review by Mann et al. (2007) indicated that there is no evidence for either sustained weight loss or health benefits from the diet approach (the evidence concerning the failure of this approach is not inconsiderable, i.e. Lagerros & Rossner, 2013; Polivy & Herman, 2006; Naheed, 2012; Ogden, 2010). Within Shea et al.'s paper, the experts agree that diets are generally doomed to failure as they don't target the root cause of the obesity and don't provide sufficient support or education regarding how to cope with the obesogenic environment. Chipman (2015) state that, although there is a clear basis for such recommendations, "experts ... point out that the complexity of the condition means that most lifestyle-based programmes are only aimed at part of the problem". McKinsey and Co (2014) recommend that a "systematic, sustained portfolio of initiatives, delivered at scale, is needed to address the health burden." NICE recommend, in sections 1.3.3 and 1.3.4, that GPs stress the clinical nature of obesity to diminish the importance of the appearance issues with obesity, although this seems rather inadequate considering the cultural disapproval of the overweight. The guidelines also suggest that GPs discuss attitudes and beliefs around eating and weight, and be aware of a patient being 'ready' for change. It is unlikely that, within a typical GP appointment, there is time to cover these areas in sufficient detail, or in such a way as to address any psychological components to the condition. Davies (2007) cautions that individuals with more extreme obesity may have psychological issues that will not be addressed by surgery or pharmacological approaches; it is reasonable to assume that psychological issues may exist that will not be addressed by diet and exercise either, regarding drivers of behaviour and behaviour change. The need to look for additional treatment approaches and consider the psychological aspects of obesity seems clear.

The behaviour change challenge: The challenge of behaviour change is also clearly present when considering dietary and exercise behaviour. Changing habits is recognised as difficult (Polivy and Herman, 2002). The importance of appropriate support in both handling changes for health and maintaining health has been documented (i.e. McCormack et al., 2015; McDonough et al., 2014; Rackow et al., 2015). Annesi and Walker (2010) suggest that supported physical activity should be introduced early on in treatment with periodic counselling, focusing on self-efficacy and perceptions of success.

Their study (lasting 24 weeks) recommended using measures such as process-related markers (increasing duration of exercise), mental wellness and increases in energy, in addition to the usual weight and similar physical measures (such as waist circumference), as relying purely on such these usual measures of success can be demotivating. Improvements in self-perception, especially around physical self, is a particularly motivating factor.

Undeniably, obesity is a complex condition. Our understanding is incomplete. Our current approaches are failing. There is a general consensus that we need to recognise the need for input from multiple approaches, as well as support and options within the wider community for individuals to engage in new behaviours. The NICE guidelines do not include advice regarding psychological approaches yet, with the challenges around behaviour, the burden of stigmatization as well as the complex connection between obesity and mental health (Chipman, 2015), psychological approaches could well play an important role as one of the multiple approaches to be used in both the treatment and prevention of overweight and obesity.

Objectives: To establish whether psychological approaches provide better long term weight reduction outcomes than diet and exercise alone, for adult individuals who are classified as obese (BMI > 30). The hypothesis being that psychological approaches to obesity produce better sustained weight loss than lifestyle approaches alone in an adult obese population.

Methods

Eligibility criteria:

- 2000 onwards: WHO and HSCIC (Health and Social Care Information Centre, 2015) data indicate scarce data prior to the mid to late 90s, from which point data is more freely available and indicate that obesity levels are rising.
- Published status: Studies that are published or awaiting publication; poster presentations; conference presentations. Papers were selected that were published in English.
- Obese adult participants: The participants were adults (18 years and over), classified as obese (BMI > 30). Evidence suggests that the risks of additional health conditions and risks increase at a BMI of 30 and above; this particular group of adults typically have tried many dieting and weight-loss approaches and may feel somewhat 'resistant' to sustained weight loss.
- Long-term outcomes: A commonly accepted definition of long term weight loss is a loss of between 5-10% of starting body weight, maintained for at least 1 year (Wing and Hill, 2001, in Wing and Phelan, 2005). As such this review examined the long term (> 12 months) weight loss outcome. It is acknowledged that interventions can lead to significant health outcomes other than weight loss, such as reduction in pre-diabetic and diabetic symptoms, blood pressure and cholesterol levels. Any significant positive outcomes in these areas were noted but were not the specific focus of this review.
- Psychological interventions: Diet and exercise do not directly address psychological aspects associated with obesity. This review examines the efficacy of including a psychological intervention. This includes a broad range of interventions including CBT, mindfulness, Motivational Interviewing, self-regulation techniques, individual work as well as group work.

- **Comparison:** Outcomes will be compared with the lifestyle approaches recommended by current NICE guidelines (the mainstays of best practice in the treatment of obesity).

Exclusion criteria:

Studies that included pharmacological or bariatric surgery approaches were excluded (steps 3 and 4 of the NICE guidelines). This review focused on a comparison with the lifestyle approaches (diet and exercise) as these are consistent throughout the NICE guidelines and the most commonly recommended approaches.

A copy of the PICO is available in the appendix (1).

Information sources: As this review assessed psychological techniques, databases that were likely to include psychological approaches were used: EMBASE, PsycINFO, PsycARTICLES, PubMed, and Cochrane. In addition to this, the reference lists of selected articles were scanned for additional relevant studies and experts in the field were contacted to request any, as yet, unpublished research as well as to gather additional views on the area of study (a list of experts contacted can be found in the appendix (4)).

Search: A full list of search terms are included in the appendix (2).

Study selection: After the initial search, the results from each database were checked for duplicates. The resulting list went forward to the first sift.

First sift: The titles and abstracts were assessed against the eligibility criteria; those not meeting the criteria were excluded. Inter-library loans were used to provide the missing abstracts at this stage. The remaining list went forward to the second sift.

Second sift: A second check was made for duplicates (i.e. same study being produced under different titles in different journals). Efforts were made to gain the full research papers for search results existing only as abstracts or poster presentations/conference reports. The resulting full papers were checked against the eligibility criteria and those not meeting the criteria were excluded. The remaining papers formed the basis of the review.

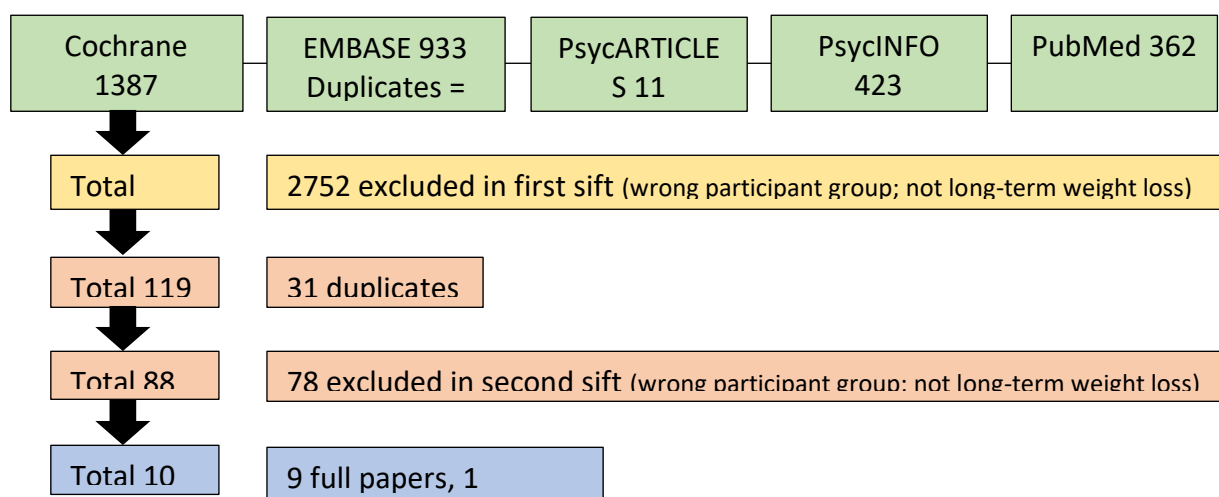
Data collection process: Quality assessments were made using the EPHPP quality assessment tool for quantitative studies (EPHPP, 2010). This tool was chosen due to its applicability to designs other than RCTs (Amijo-Olivo et al., 2012) and is appropriate for systematic reviews assessing effectiveness such as this (Deeks et al., 2003). Papers achieving a weak rating did not proceed to data extraction.

Results

Study selection: The searches produced a total of 3116 titles across the 5 databases used. 235 were found to be duplicates and 5 books had appeared in the search results. The remaining 2987 went through to the first sift.

- *First sift:* The first eligibility assessment was made on the basis of titles and abstracts. Inter-library loans were used to provide the missing abstracts at this stage where necessary. 2757 were excluded at this stage, leaving 119 papers to review in full.
- *Second sift:* From the full paper review, 31 papers were found to be duplicates and a further 78 papers were excluded based on the eligibility criteria. Of the remaining 11 papers, 8 had been published and were freely available. Requests were made for the missing papers. Only one additional paper was gained this way (a paper in press). The paper being written up did not contain sufficient information to include (not enough information on the intervention to be sure it contained a psychological component). This resulted in a total of 10 papers to be reviewed (including one as abstract only).

Figure 1: Flow chart for search and identification of relevant research



Key



Study characteristics: Of the 9 full papers selected for this review 8 were randomised controlled trials and one was an observational cohort study. Quality assessments were made using the EPHPP quality assessment tool for quantitative studies on the full papers. The quality assessment ratings can be found in full in the appendix (3). Three were rated as strong, two as moderate and the remaining four as weak.

Synthesis of results/method of analysis: As the review covered a range of psychological interventions rather than just one, synthesis of the results for the purpose of meta-analysis was not indicated. As such a narrative synthesis approach has been adopted. Only the 5 papers rated as strong or moderate were used for data extraction purposes.

Table 1: Data extraction table

Author	Participant no. IG	Participant no. CG	Psychological intervention	Duration of intervention	Follow ups and timeframe	Weight loss outcome	Other outcome
Daubenmeier et al., (in press)	100	94	Mindfulness training for stress management in eating and exercise (face to face)	5.5m	3, 6, 12 & 18 months	p=0.06 at 12 months (4.3 – 5.1% at 18 months)	Trig./HDL levels; fasting glucose levels
Hardcastle et al., 2013	203	131	Up to 5 face to face motivational interviewing sessions	6	Post intervention and 12 months	NS	Improved HDL, LDL & Trig.; increased physical activity

Stahre & Hallstrom, 2005	62	43	Cognitive group treatment programme (face to face)	10 weeks (30 hours)	After treatment, 6, 12 & 18 months	p=0.001 (9% at 12 months)	Low attrition
Donini et al., 2014	182	282	Multidisciplinary multicomponent including group cognitive-behavioural psychotherapy (face to face)	Dependent on 10% weight loss	4 years after first visit	p<0.001 (=> 10% at end of period)	Improved physical activity and healthy dietary habits
McConnon et al., 2007	111	110	Website offering general and personalised advice and motivational statements (not face to face)	Not limited	6 & 12 months	NS	Noted – 53% using website at 6 months and 29% at 12 months

Findings: There was moderate evidence of psychological interventions improving long term weight loss in obese adults, with three of the studies included at the data extraction stage showing significant long term weight loss outcomes. Two studies showed significant improvements in other risk factors measures (triglycerides, HDL/LDL levels and fasting glucose). One study showed a significant improvement in both physical activity levels and healthy dietary habits. Of the two studies without significant weight loss outcomes, one was based on participant-led contact with a website only (no face to face contact). Only 53% of participants were using the website at 6 months, dropping to only 29% at 12 months. The other study without a significant weight loss outcome was a motivational interviewing (MI) intervention, where participants decided how many (of up to 5) MI sessions to take part in. The mean number of sessions attended was 2 with only 12% of participants electing to attend all 5 sessions. Despite the lack of significant long term weight loss, this study did find significant improvements in HDL, LDL and triglyceride levels and a significant improvement in physical activity levels.

- **Studies resulting in significant weight loss:** Daubenmeier et al., Stahre and Hallstrom, and Donini et al.. These three studies were markedly different regarding the contact time and type with the participants. They all included weekly, group, face-to-face time with an instructor/group facilitator, although the duration of this contact varied. The sessions were based around thoughts and approaches to eating and eating behaviour, elements of stress management and sessions/coaching regarding diet and exercise. This is in-line with the recommendations of experts, that individuals should receive support and that focus be given to the factors driving and maintaining disordered eating practices (as well as approaches to exercise).

- Daubenmeier et al. (EPHPP rating: Strong) consisted of a 5.5 month diet-exercise intervention. There were sixteen 2-2.5 hour sessions; 12 weekly, 3 biweekly, and 1 monthly, plus one day session. The diet and exercise guidelines were given in 45 minute sessions. The intervention group had mindfulness training (for stress management, eating and exercise) and the control group had extra nutrition and exercise input as well as progressive muscle relaxation and cognitive behavioural training to control for the mindfulness approach. The overall outcome showed support for the inclusion of mindfulness in weight loss programmes. The researchers also note that the randomisation of participants may have led to participants with no interest in mindfulness being allocated to that arm of the study. Attrition during treatment was 26%. The researchers noted in their paper that blinding, in such studies, is almost impossible and not necessarily desirable. Their analysis of the drop-outs from the mindfulness arm of the study suggested that these individuals were less interested in the mindfulness component. This, they felt, suggested that "...participant engagement is important and individuals with obesity who do not express interest in mindfulness approaches may respond less favourably..."; the issue of treatment motivation is something to consider regarding any psychological behaviour change intervention.

An additional finding relates to the role of the trainer/instructor. Three different mindfulness instructors were used, one of which was rated as being 'less helpful'. The researchers ran additional analysis factoring in instructor as a variable and found that there was a significant difference in weight loss between instructors A and B (combined) compared to instructor C (6.3 – 2.0 kg loss respectively, significance of $p=0.02$). Supervisor observations indicated a stricter adherence to the treatment manual by instructors A and B ("...at the possible cost of fuller personal engagement with group participants..." p11). The researchers express caution regarding interpretation of these differences, however, it is notable that there was a significant weight loss difference between the instructors' groups, which persisted to 18 months.

When data from the three instructors were combined, the mindfulness arm still produced better long term weight loss than the control, indicating support for the inclusion of a psychological component in weight loss programs, in this case, mindfulness for stress management, eating and exercise.
- Stahre and Hallstrom (EPHPP rating: Strong) consisted of 30 hours of a group-related cognitive programme across 10 sessions, given once a week. The intervention group focused on "...possible causes underlying the dysfunctional eating behaviours rather than on eating behaviour per se. Special attention was given to deficiencies in self-control, low self-esteem and experiences of stress." (p53) The control group remained on the waiting list for treatment. 57 of the original 62 within the treatment group completed the treatment (8% attrition during treatment); by 18 months this had dropped to 34 (40% attrition in follow-up). All participants volunteered for the study and were then randomly allocated to the

treatment arm or control group. The interest in working psychologically was indicated by their initial interest in the study and may be related to the low attrition rate (for treatment).

This study shows support for examining the motivations and thought processes that drive eating behaviour.

- Donini et al. (EPHPP rating: Moderate) consisted of a multi-dimensional multi-disciplinary Nutritional and Psycho-Physical Rehabilitation Program (NPPRP). Participants were provided with an individualised diet. The NPPRP also included physical reconditioning and rehabilitation; group cognitive-behavioural psychotherapy; and educational activities across nutrition, exercise and the therapeutic approach. Their time commitment was 4 hours for 2 days a week. The treatment was target- rather than time-limited. Attrition during treatment was 5% compared to 45% in the control group (who received individualised diet plans and advice regarding exercise). Participants self-allocated themselves to either the NPPRP or control group. The self-selection into the treatment arm may be related to the low attrition rate, as in Stahre and Hallstrom and suggests that inclination to work psychologically may be a predictor of success with such an approach.

This study supplies support for an approach which works across a number of areas, diet, exercise and underlying psychology.

- **Additional outcomes/factors of interest:**

1. It is notable that the three studies with significant weight loss also noted other significant improvements in measures such as triglyceride and HDL levels, as well as improvements to physical activity levels. One of the studies that did not have significant weight loss as an outcome did find significant improvements in HDL, LDL and triglyceride levels and an improvement in physical activity levels.
2. Face to face time: Of the five full papers analysed, four offered face to face time with an instructor/therapist. These four studies found significant improvements in weight and/or other key measures of risk factors. The study with the least face to face time of those four did not show a significant result regarding long term weight loss (although there were significant changes in HDL, LDL and triglycerides as well as physical activity levels). The three studies with significant face to face time with participants all showed significant long term weight loss outcomes.
3. Attrition in weight-loss treatment is a particular issue. There is evidence here to suggest that both treatment motivation and engagement (therapeutic alliance) may be significant factors in the effectiveness of psychological interventions for obesity, and requires further investigation.

Summary

There was moderate evidence that psychological interventions were successful in producing long term weight loss outcomes. Analysis also indicated that there were other positive health outcomes such as reduction of triglyceride, HDL/LDL levels and fasting glucose. It is noted that selection bias was an issue in most studies. A key factor was the use of participants that volunteered, producing a potential bias. Actively seeking support plays a significant role in the success of any approach to obesity however. It is also important to note that psychological approaches need to be suited to an individual;

engagement is key, as individuals need to be inclined to work psychologically. Some individuals are not motivated to, or wish to, work psychologically. Randomisation was explained and justified in the strong and moderate studies however, it was acknowledged within some reports that randomisation was not an ideal approach (for the reason stated above). Blinding, along with selection bias and randomisation, is another aspect where there is a case to be made regarding relevance to the area. Participants should be aware of the specifics of an intervention in order to make an informed judgement on whether they wanted to take part or not.

There were no important differences between intervention and control groups, prior to the intervention, in any of the studies included. It should be noted however, that there were always more women. This reflects the general scenario regarding individuals seeking treatment for obesity (Atlantis and Baker, 2008). The reliability and validity of data collection tools was not always reported well, an aspect of importance regarding assessments of psychological constructs where a variety of tools are available. Psychological constructs were beyond the focus of the current review, however, building a clearer picture of psychological constructs in relation to obesity is something which would benefit from more research. Withdrawals and drop-outs were handled well overall with five studies rated strong and the remaining four as moderate. The better reporting included more detail of the reasons for drop-outs and withdrawals, something which became especially relevant within the Daubenmeier et al. study. Attrition in weight loss programmes is a common problem; exploring the reasons for withdrawal in greater detail may provide valuable insights.

Intervention integrity is a more complex issue with a psychological intervention, especially when using multiple staff for delivery. This complexity was reflected in the ratings with only one study being rated as strong, seven as moderate and one as weak. Reasons for this varied: some studies did not have a large percentage of participants receiving the intervention after allocation from exposure of interest; it was deemed possible for participants to be conducting other weight loss activities, more so in some studies than others, particularly those with less or no face to face contact time; but consistency of the intervention was only handled directly in one study (Daubenmeier et al.) where a disparity in the effectiveness of different deliverers of the intervention was found (noted above). Analysis was moderate in seven of the papers and strong in two, with some studies not pursuing an intention-to-treat analysis.

The type of intervention varied in terms of contact hours, type of contact and intervention. Some studies left it to participants to determine how much contact they had with the intervention (these did not provide a significant weight loss outcome although one of these studies did produce other significant positive health outcomes), whereas others involved a specific number of hours and sessions (all of which produced significant weight loss outcomes as well as some additional positive health outcomes). The additional positive health outcomes were triglyceride levels, HDL and LDL levels, fasting glucose levels, levels of physical activity and healthy dietary habits. Attrition rates, typically a big problem with obesity interventions, were also noteworthy in some studies.

Discussion

Summary of evidence: Significant and sustained weight loss was evidenced from the inclusion of psychological approaches in weight loss programmes, when compared with standard lifestyle approaches (diet and exercise). This appears to be related to: support and contact time with the instructor; the interaction with the participants; and the motivation of the participant to engage with the intervention offered. Considering the body of work around therapeutic alliance and treatment motivation, these particular outcomes are unsurprising. It is of further note that, in the study where weight loss did

not reach level of significance, there were significant and positive health outcomes relating to triglycerides, HDL and fasting glucose levels as well as improved dietary and exercise habits. Studies which had little or no contact time with participants did not produce sustained weight loss outcomes. The psychological approaches that did produce positive outcomes focused, typically, on the underpinning drivers of dysfunctional eating and stress management (Daubenmeier et al., in press and Stahre and Hallstrom, 2005). This suggests that the typical diet and exercise approaches, without additional support, may need to be reviewed. The current review is an indication that psychological approaches could at least be included within the next consultation for NICE guidelines.

The lack of long-term studies, focusing purely on the obese adult population, indicates the need for further research in this area as the existing studies indicate the potential for better long term outcomes. The impact this could have on healthcare providers is considerable. Considering the current financial cost of obesity and obesity related conditions to the NHS, approaches which offer long-term reductions in risk could reduce this burden considerably, also off-setting costs of setting up new psychological treatment options; more research is required in this area, including cost-effectiveness studies of weight loss approaches that include psychological interventions. Within the Specialist Weight Management Services at National Health Service hospitals, some psychological approaches are already being used, and some Clinical Commissioning Groups are buying in services which incorporate psychological approaches. Establishing which approaches to offer and for how long would be helpful in terms of clarifying guidelines.

The existing referrals for diet or exercise from primary care providers typically last for 12 weeks. The duration of these referrals may not be an issue if we consider the success of Stahre and Hallstrom whose intervention ran across 10 weeks (a total of 30 hours). It appears that the nature of the treatment and support received during the referral requires examination with a view to adding psychological components to the referral schemes. As mindfulness, cognitive-behavioural and motivational interviewing approaches all indicated positive outcomes, and taking into account the importance of engagement and interest in the approach on offer, a range of additional psychological treatments could be offered. For the obese population, these approaches offer an alternative that could potentially break the demoralising and depressing loss-regain cycle. Daubenmeier et al. (in press) noted that individuals that withdrew indicated a lack of interest in the psychological approach they used (mindfulness); fitting the individual to the right approach is not something to be overlooked. Treatment motivation from patients has been noted as a key factor regarding outcomes due to the importance of the patient's active engagement in the psychological approach (Krause, 1967) and, as such, is closely allied to the patient's choice of treatment. Daubenmeier et al. also noted a disparity on effectiveness between the different instructors with one instructor being rated as 'less helpful' than the other two; the practitioner's skill and ability is something that requires further research regarding weight loss approaches. Krupnik et al. (1996) note the significance of the therapeutic alliance to outcomes regarding treatments for depression and Martin et al. (2000) acknowledge that this is the case across a wide variety of treatments. The quality and bias measures that relate specifically to blinding and randomisation then do not fit well with psychological interventions. A study found during the search phase, Ribot et al., 2013 (abstract only), found that participants lost significantly more weight when they had signed a 'therapeutic commitment contract' at the start of treatment. The treatment appears to have been dietary-based only but the weight change between the intervention and control group at both 12 and 18 months was found to be significant at $p < 0.05$. If the act of making a conscious commitment to a

programme holds significance in a treatment's efficacy then we need to question the role of randomisation in treatment assessments.

Limitations: The number of studies meeting the eligibility criteria was relatively small. In particular, the term 'obese' was often used to cover those who were also overweight (frequently including participants with BMIs of 28 as a starting point for eligibility). This review aimed to examine the impact of psychological interventions on the treatment-resistant obese population, however, it is acknowledged that a similar review including the overweight population would be of use regarding policy-making and health care provision with prevention in mind. The length of studies was a key limiter; studies which assess up to 6 months post-treatment were more common. The gains to the individual in terms of reduced risk as well as the gains to health care providers and governments in terms of reduced costs are more notable with sustained weight loss though. Encouraging more studies to extend their follow-ups would be beneficial.

The range of psychological interventions counter-indicated the use of a meta-analysis within this review. A review that considered particular approaches would provide better opportunity for meta-analysis. Attrition is a common issue in weight-loss approaches which, arguably, places greater emphasis on studies to address the issue of missing data. This was not always adequately addressed within the studies identified by this review.

Conclusions: This review provided moderate evidence for the inclusion of psychological interventions within weight loss programmes for obese adults and suggests that there is a need for more research around the long-term outcomes for psychological approaches to weight-loss. The studies identified suggest that the type and quality of the contact with the individuals is of particular importance regarding outcomes but also that outcomes other than weight-loss need to be considered (such as cholesterol levels, as well as dietary and exercise habits). Active engagement in the treatment option and therapeutic alliance are also factors that need to be considered, such that the issue of blinding and randomisation may not be appropriate within such studies. Adding psychological treatment options to the current diet and exercise referrals from primary care has potential to improve long term weight loss outcomes in an obese population.
(word count 5960)

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Appendix

1. PICO form and search strategy

Question: Are psychological interventions effective in reducing weight long-term, in an obese population (BMI > 30), compared to lifestyle interventions (diet and exercise)?

Population: Obese adults, BMI > 30; Aged 18+

Intervention: Psychological

Comparison: Lifestyle (diet and exercise)

Outcome: Long-term weight loss (12 months+)

Study design: RCTs with follow-up; longitudinal; observational cohort; time series; qualitative; quasi-experimental

Source/databases: EMBASE; PsycINFO; PsycARTICLES; PubMed; Cochrane Library.

Years: 2000 - present

	Population	Intervention	Comparison	Outcome	Study Design	Limits
	AND	AND	AND	AND	AND	NOT
O R	Obese	Psychological	Diet	Long-term weight loss	RCT	Bariatric surgery
O R	BMI > 30	Self-regulation	exercise	Sustained weight loss	Longitudinal	Pharmacological intervention
O R	Overweight	Mindfulness	Diet and exercise	Weight loss	Time series	
O R	Morbidly obese	Support groups	Lifestyle		qualitative	
O R	Obesity	ACT			Quasi-experimental	
O R		CBT				
O R		Positive interventions				
		GMCBI (group mediated cognitive behavioural intervention)				
		Cognitive behavioural intervention				
		Stress Management				

		DBT				
		Self efficacy				
		Body satisfaction				
		Psychoeducational				
		Community Interventions (to include internet communities)				
		Behavioural interventions				
		Team-based				
		Self determination				
		Motivation				
		Therapeutic (therap*)				
		Internet-based weight loss programme				
		Flexible cognitive restraint				
		Disinhibition				
		Counselling				
		Family support				
		Mobile phone based				

2. Search terms

obes* OR overweight OR "over-weight" OR "BMI>30" AND psychological OR "self-regulation" OR mindfulness OR "support group" OR ACT OR CBT OR DBT OR "positive intervention" OR "group mediated cognitive behavioural intervention" OR "cognitive behavioural intervention" OR "stress management" OR "self efficacy" OR "body satisfaction" OR psychoeducational OR "psycho educational" OR "community based" OR "self determination" OR motivat* OR therap* OR "internet based weight loss" OR "flexible cognitive restraint" OR disinhibition OR counsel* OR "family support" OR "mobile phone based weight loss" AND diet OR exercise OR lifestyle AND "long term weight loss" OR "long term weight reduction" OR "sustained weight loss" OR "sustained weight reduction" OR "weight loss" OR "weight reduction" NOT bariatric OR pharma*
 Built-in limiters used: human participants; papers in English or translated into English; adult participants (18+).

Initial searches included a high number of studies focussing on weight loss in cancer. As this was not the focus, an additional limiter of "cancer" was used.

The limiter for pharmacological interventions was allowing through studies that used names of specific medications, the most common of which was orlistat. "Orlistat" was added as an additional limiter. With the additional limiters in place the searches were run again.

3. EPHPP ratings table

Authors	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawals and drop-outs	Intervention integrity	Analyses	Overall rating
Bacon et al., 2002	2	1	1	3	3	1	2	2	Weak
Carels et al., 2005	3	2	1	2	3	2	2	2	Weak
Daubenmeier et al., in press	1	1	1	1	1	1	1	1	Strong
Donini et al., 2014	2	2	2	3	1	2	2	2	Moderate
Gohner et al., 2012	2	1	1	3	3	1	2	2	Weak
Hardcastle et al., 2013	2	1	1	2	1	1	2	1	Strong
McConnon et al., 2007	2	2	1	3	1	2	2	2	Moderate
Stahre & Hallstrom, 2005	2	2	1	2	1	1	2	2	Strong
Yardley et al., 2014	2	1	1	3	1	2	3	2	Weak

Key: 1 = strong; 2 = moderate; 3 = weak.

No weak ratings = strong; one weak rating = moderate; two or more weak ratings = weak.

4. Experts contacted

Jamie Blackshaw. Team Leader for Obesity and Healthy Weight, Public Health England

Professor Susan Michie, Centre for Behaviour Change, University College London

Professor David Haslam, Chair of the National Obesity Forum

Dr James Annessi, Director of Wellness Advancement, YMCA or Metro Atlanta

Profesor Johannes Hebebrand, Vice President, northern region, of the European Association for the study of Obesity