Exploring the onset, maintenance, treatment and recovery of eating disorders from the perspective of New Zealand women with lived experience: A mixed methods approach

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by
Roma Watterson

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Preface

The research that constitutes this thesis was conducted as part of a larger collaborative project entitled ‘The Costs of Eating Disorders in New Zealand’ (known going forwards as the ‘COSTS Study’). The larger COSTS Study, and the components which were relevant to the present research, are described within the thesis. I contributed to the larger project in a variety of ways. In order to meet the aims of this PhD, I introduced a number of new and amended items to the online survey for those with a history of an eating disorder, expanded the interview schedule for those participants, and applied for and obtained ethical approval for all changes. I also subsequently updated the COSTS Study webpage to reflect those changes. I was responsible for the data collection over a period of 18 months. I distributed posters and revisited poster locations to ensure they were maintained, advertised across social media, and wrote advertisements that were posted online. Furthermore, I responded to email and telephone enquiries, and initiated contact with survey participants who met the inclusion criteria and advised they were happy to take part in further research. I conducted all of the interviews with the 18 participants from which the data was obtained for the qualitative part of this thesis. I transcribed all of the interviews in full, including those questions which pertained to the larger study rather than the present thesis. I also carried out all of the data analysis for this PhD, across both the quantitative and qualitative studies, comprising of univariate analyses (t-tests, ANOVA, Mann-Whitney U tests and Kruskal Wallis tests), regression models and thematic analysis. I presented subsets of my findings at the Australia and New Zealand Association of Eating Disorders Annual Conference 2019 in Adelaide and the New Zealand Psychological Society (NZPS) Annual Conference 2019 in Rotorua. At the latter conference, I was the winner of the best student presentation and was invited to write an article for *Psychology Aotearoa*, the NZPS newsletter. The article included a brief overview of some of the preliminary findings from Study 2. Full findings are reported within the PhD.

Abstract

Eating disorders (EDs) are a group of mental health illnesses (anorexia nervosa, bulimia nervosa and binge eating disorder) that can have serious and sometimes fatal health consequences. Existing research indicates a wide range of etiological factors. Key psychological and social causal factors established in the literature include: low self-esteem, emotion regulation difficulties, an external locus of control, high perfectionism, high body dissatisfaction, trauma (particularly sexual abuse), relationship struggles with parents and/or peers (including bullying) and peer pressure. Interestingly, a number of these psychological and social factors also reoccur in the literature examining the maintenance of EDs. It is accepted that multiple, rather than a single factor, contribute to both onset and maintenance, and these factors vary not only among ED diagnostic groups but also between individuals.

Despite the body of existing literature, the complexity of EDs means that etiology and maintenance is still not fully understood. Further, treatment dropout and recovery rates show there is still significant room for improvement. Despite the unique insights participants with lived experience of an ED can provide, few studies have focused upon their perspective. Research from the perspective of women with binge eating disorder is particularly limited. No studies were identified that explored patient views of causes, maintenance factors, treatment and recovery within the same sample. This lack of research looking holistically at experiences of an ED has restricted the ability to explore how perceptions of causal and maintenance factors may be connected to treatment experiences and, thus, recovery. Furthermore, research comparing the perceptions of people with different ED diagnoses, is extremely scarce; very few qualitative studies and no quantitative studies were found, despite quantitative methods enabling statistical comparisons between groups. Yet, establishing diagnostic differences may have important implications for tailoring treatment based on ED diagnosis to improve efficacy. Finally, no research was identified that used mixed methods

within the same sample, yet for a complex topic such as eating disorders, triangulation through mixed methods can strengthen any conclusions or implications.

The present PhD sought to address the research gap by exploring the perspectives of women with a history of anorexia nervosa (AN), bulimia nervosa (BN) and binge eating disorder (BED), through a mixed methods approach. The specific purpose was to investigate the key psychosocial factors that influenced the onset and maintenance of an ED, and factors that participants perceived were linked to effective treatment and recovery.

Study one utilised an online survey to collect quantitative data to examine the extent to which psychological and social causal and recovery factors, identified through the literature review, were perceived to be important by women with lived experience of an ED ($N = 358$). Results indicated that all of the causal factors explored were endorsed by at least 43% of participants, demonstrating the broad range of factors perceived to be involved in the onset of an ED. Low self-esteem, difficulties coping with negative emotions and feeling pressure to succeed and be perfect were the most highly endorsed causal factors across all ED diagnostic groups. Perceptions of feeling a sense of control from the ED differed significantly between each diagnostic group; participants with AN were significantly more likely to endorse this causal factor and participants with BED were significantly less likely. Participants with BED also differed from those with AN and BN in their views of several key recovery factors; they were more likely to endorse the use of support groups and tackling issues around food and body image. Self-motivation was found to be the most important recovery factor across all diagnostic groups.

In study two, a qualitative study, a subset of women from study one ($n = 18$) were interviewed to explore their views on the onset, maintenance, treatment and recovery of their ED. Through thematic analysis, seven themes were identified: perceptions of being in or out of control, “people always compliment you for losing weight”, difficulties in being one’s true

self, judging oneself negatively in comparison to others, emotion regulation, misconceptions of what a ‘legitimate’ eating disorder looks like, and a change in perspective. Participant narratives highlighted a variety of psychological and social factors that were relevant throughout the different stages of an ED, from onset to recovery. A number of barriers to help-seeking were also described, which, in addition to viewing the ED as serving a positive function, were perceived as central maintenance factors.

The weaving method of narrative integration was used to provide a comprehensive discussion incorporating both sets of findings. A high level of convergence between the quantitative and qualitative findings was evident. Several psychosocial factors reoccurred as important to onset, maintenance, treatment and recovery. Some diagnostic differences were also established. In summary, low self-esteem and high perfectionism appeared to influence a tendency to make self-comparisons and the way in which compliments were internalised (such as pressure to maintain a high standard). Low self-esteem also appeared to foster a fear of abandonment, which resulted in participants supressing needs or concerns in favour of pleasing others. This lack of self-expression appeared to decrease the use of social support as a coping strategy and had implications for engaging in a therapeutic relationship. In addition, a need to feel in control and difficulties regulating emotions made coping with trauma and distress problematic, resulting in using an ED as a coping strategy. These integrated thesis findings were developed into a psychosocial model to illustrate the links between the psychological and social causal factors, and how these psychosocial processes impacted upon the maintenance of an ED, the treatment and recovery.

Implications of the findings for the prevention of EDs include greater focus on changing media portrayals of appearance and weight loss, and the delivery of media literacy programmes. Greater education around EDs is needed, for the public and professionals, to remove stigma and to break down barriers to accessing treatment. The results also have wide

ranging implications for treatment, which include ensuring a sense of autonomy, enhancing self-motivation, addressing the perceived positive function of an ED, careful consideration of using compliments and criticism, teaching healthy coping strategies, and the importance of incorporating diagnostic and individual differences into treatment plans.

CHAPTER ONE: Setting the Scene

1.1 Introduction

This thesis explores a group of mental health illnesses known as eating disorders (EDs). While there is a body of literature investigating the many different aspects of EDs, including a range of potential causal factors and treatment options, there are still many knowledge gaps. The focus of this PhD is on the views of women with lived experience of an ED. Although their opinions cannot be accepted as fact, they provide a unique and potentially very elucidating perspective on these complex disorders that can vary considerably between individuals. The research sought to gain an insight into the perceptions of women with lived experience of an ED, particularly what caused their ED, why it was maintained, what was helpful or unhelpful in treatment, and how these factors may or may not contribute towards recovery. Of further interest was any variation in views based upon diagnostic group or recovery status, and the clinical implications these differences may have for treatment. Thus, the research questions this thesis sought to answer, in a group of women with lived experience of an eating disorder, were:

1. What factors do the participants believe contributed to the onset, maintenance and recovery of their disorder, including factors within treatment?
2. How do the factors perceived to have contributed to onset, maintenance and effectiveness of treatment compare in recovered and non-recovered participants
3. How do participants' experiences and views of factors that influenced onset, maintenance, treatment and recovery vary based on their diagnosis?

The project used a mixed methods approach to address these questions, by conducting both a quantitative and a qualitative study that collected the views of women with lived experienced. The quantitative study enabled statistical comparisons based on recovery status and ED diagnosis to be made. The qualitative study allowed narrative data to be collected in a format that was unrestricted by predefined response choices. Further detail can be found in each of the relevant study chapters (Chapter 4 and 5).

1.2 Developing the Project

1.2.1 Where it all Began

Volunteering as a support worker for Rape Crisis Tyneside and Northumberland, a charity in North East England that supports survivors of rape and other sexual violence and abuse, I noticed disordered eating and food being a common subject. I decided to investigate this for my Master's thesis, interviewing counsellors about their experiences with clients and their views on the possible link between sexual abuse and EDs. This is where my interest in EDs and their causes began. After delving further into the literature it became clear that there are far more factors involved than solely abuse and I began my journey to find out more. Despite this being an active field of research, with new theories of etiology and treatment being proposed and tested through clinical trials, it was clear that there is still scope to improve and expand knowledge and understanding.

Through my volunteer work I have prior experience in speaking with women who have been through traumatic and emotional experiences. My training involved learning some counselling skills but I am not a qualified counsellor and my main training and experience is around listening. I feel that this equipped me well for this project, as I was comfortable listening to the experiences of the participants and was not interpreting their narratives from a practitioner's point of view. Furthermore, I have not experienced an ED myself and neither has anyone close to me, so my interpretations will not be influenced by having lived experience of an ED. I do however accept that I will have some personal opinions on certain topics that influence my perspective and decisions, especially having read and reviewed the background literature. Acknowledging that fact allowed me to try and be mindful of my own beliefs and remain as open as possible.

1.2.2 The Costs of Eating Disorders in New Zealand (The COSTS Study)

As outlined in the preface, the research that constitutes this thesis was conducted as part of a larger study, the COSTS Study, being run by the University of Otago, Christchurch, with co-investigators at the Eating Disorders Association of New Zealand (EDANZ), Canterbury District Health Board, University of Auckland, and the University of North Carolina & Karolinska Institutet. The COSTS Study had broader aims of obtaining information about the impact of EDs in New Zealand, including financial and other costs, from both people with a history of an ED and carers of someone with an ED. It also included an additional section eliciting participant views of causality and recovery.

1.3 Ethics

Approval had already been granted from the Health and Disability Ethics Committee (HDEC) for the original COSTS Study. Following my addition to the research team and the subsequent amendments and additions made for this PhD, a further application to the HDEC was made. The changes received approval from the HDEC on 19th October 2017 (ref: 16/NTB/189/AM01) (see Appendix A).

1.4 Thesis Structure

The present chapter provides an overview of the origins and research questions underpinning the thesis. Chapter 2 introduces the topic, key terms and approaches taken in the project. The philosophical position and theoretical framework that underpin the thesis and guided methodological decisions are set out. The rationale for the mixed methods approach is also discussed. What is meant by the term ‘eating disorders’ in this thesis is defined in Chapter 2, as is a brief overview of treatment of EDs in New Zealand. Current knowledge on the epidemiology of these illnesses is also reviewed, providing background information that begins to emphasise the importance of this area of research and places the current project in context. The additional key constructs: ‘causal factors’, ‘maintenance factors’ and ‘recovery’, which are a focus throughout this thesis, are defined.

Chapter 3 provides a review of current literature on the etiology and treatment of EDs. Throughout this review the distinction is made between the results from quantitative studies and the results from qualitative research from the perspective of people with lived experience of an ED. This structure allows for a comparison to be made between the findings generated by the two methods and subsequent conclusions drawn. Chapter 3 concludes by providing an outline of the aims and objectives of the overall project.

The thesis consists of two different studies; the quantitative study and the qualitative study. Chapter 4 presents the quantitative study, including the method of data collection, the data analyses conducted, and the results found, which are discussed in relation to other research. The strengths and limitations of the quantitative study, and implications of the findings, are also considered. The qualitative study is presented in Chapter 5, including the methods used and the themes identified. A discussion of the findings in reference to existing literature, the strengths and limitations of the study, and the implications, are also presented.

The mixed methods approach here utilised a convergent design, meaning each study was conducted and analysed separately and then brought together for a final interpretation (Creswell & Plano-Clark, 2011). This integrated interpretation is presented in the final chapter, Chapter 6. Using the weaving method of narrative integration (Fetters et al., 2013), the findings from the quantitative and qualitative studies were incorporated together into an overall discussion. The discussion is separated into each of the key psychosocial concepts that were identified in the data. For each concept, the relevant results generated from each method are outlined, establishing the extent to which the two methods aligned or diverged, and are then considered alongside existing literature. Finally, implications of the integrated findings are considered and future directions for research are proposed.

CHAPTER TWO: Background and Thesis Context

2.1 Introduction

The purpose of this chapter is to place this thesis in context. Firstly, the ontological and epistemological assumptions and the underpinning theoretical framework for the project are explained. Next, some contextual information about EDs is provided, including the different diagnostic criteria between each ED. Epidemiological and treatment information is reviewed. Finally, key definitions are provided.

2.2 Ontology and Epistemology

This is a mixed methods research project. As described by Johnson et al. (2007), "mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purpose of breadth and depth of understanding and corroboration" (p. 123). Utilising the strengths of both methods can enhance research, but some writers have proposed concerns that quantitative and qualitative methodologies are underpinned by different world views (Holloway & Galvin, 2017). It was therefore important to clearly establish the philosophical approach this project took and how this guided the decisions made throughout. The project was carried out under the assumption that there is a world independent of human existence but our social experiences determine our knowledge and shape our perception of reality. Therefore, the project was conducted from a critical realist position. Critical realism first emerged out of a critique of the positivist epistemology in the 1970's and particularly through the works of Roy Bhaskar (Danermark et al., 2005).

Positivism focuses on that which is observable and quantifiable, keeping interpretations separate to the data (Kvale, 2007). This is closely linked to quantitative methodologies, which conduct experiments to test hypotheses and consider the researcher as an impartial observer (Johnson & Onwuegbuzie, 2004). Critical realism, however, takes the position that the focus should be switched to ontology, understanding what constitutes reality, and the underlying mechanisms that are causing events rather than the events themselves. There is an independent reality, of which not all aspects are observable, but these aspects can still be experienced and studied indirectly through their ability to cause events (Danermark et al., 2005). When studying human participants, it is from the position that although an independent reality exists, our social world is constructed and context can impact upon the results of causal mechanisms, therefore reality cannot be entirely independent (Sayer, 2000).

It is assumed humans are active participants in the research, who have their own opinions based upon experiences. People evaluate their experiences, which may influence or change their actions, therefore researchers need to know the meanings people attribute to their actions to be able to understand the behaviours (Danermark et al., 2005). This has some similarities to idealism, which holds the position that “reality is only knowable through the human mind and through socially constructed meanings” (Snape & Spencer, 2003, p. 11) and is therefore linked to qualitative methodologies (Lipscomb, 2008). However, critical realism also holds the position that when people construct their own social reality they often make mistakes (Gorski, 2013). The fact that humans can make mistakes in their knowledge of the world is evidence of a reality independent of our existence (Sayer, 2000). There is often an ontological gap between the independent reality and human understanding of the world, and research needs to focus on both the real world and the person’s interpretations of it, as even false perceptions can influence their actions (Danermark et al., 2005).

In sum, critical realism holds some positivist (associated with quantitative methodologies) and some idealist (associated with qualitative methodologies) assumptions. Braun and Clarke (2006) refer to critical realism as “sitting between the two poles” (p. 81) and so using mixed methods research for this project is in line with the philosophical position. Although acknowledgement needs to be given to the quantitative vs. qualitative paradigm debate, mixed methods can be an effective way of addressing the research question if the potential for philosophical inconsistencies, the methods chosen, and the way they are combined are carefully considered (Johnson & Onwuegbuzie, 2004; Lipscomb, 2008). Johnson and Onwuegbuzie (2004) proposed that mixed methods research should be considered as a third paradigm, and I would suggest one that is associated with critical realism. Lipscomb (2008) described how critical realists can use empirical methods to study those aspects of reality that are measurable, and use qualitative methods to investigate the meanings and interpretations people have of the world. Therefore, there is no restriction to one aspect of ‘reality’.

The present thesis focuses upon the perspectives of women with lived experience of an ED. In line with critical realism, understanding their experiences, how they interpreted those experiences and the way those interpretations influenced their behaviours was key, whilst accepting that they may not be conscious of all the reasons behind their actions. Quantitative and qualitative methods generate different kinds of data that can be used together as a powerful tool to produce a fuller picture of complex phenomena (Ritchie, 2003). The well-established complexity of EDs provides rationale for the mixed methods approach taken here. Each individual with an ED has their own unique experience and so a methodology that allows an open exploration that is not constrained by pre-existing theories was required (Patching & Lawler, 2009). Using qualitative methods enabled the participants to describe their views, experiences and motivations in detail and relevant to different contexts.

Alternatively, quantitative research involves conducting statistical analysis to establish patterns in the data and allows for statistical comparison (Bernard, 2012). As described later in this chapter, EDs are a group of illnesses made up of several different diagnoses, the three most common of which were considered in this thesis. The use of quantitative methods allowed for a statistical comparison of the views of participants based upon diagnostic group and recovery status. Using quantitative and qualitative methods alongside each other, and bringing the findings together for a further interpretation, can provide meaning and reasoning to the numbers (Johnson & Onwuegbuzie, 2004). Using a mixed methods approach in this PhD was therefore consistent with the philosophical assumptions and the most appropriate approach to meet the research aims. The reasons behind the particular methods of data collection and analysis chosen within each study, including reference to the philosophical position, are discussed in greater detail within the relevant method sections of Chapters 4 (quantitative), 5 (qualitative) and 6 (mixed methods integration).

2.3 A Psychosocial Theoretical Framework

The Biopsychosocial Model was first proposed for use in psychiatry by Engel (1977), in response to concerns over an inadequate health care system. Engel stated that the Biomedical Model, which focuses solely on biology and was the most commonly used model at the time, does not incorporate all of the etiological factors necessary to establish the most appropriate treatment. He reported that early experiments within medicine have shown biological abnormalities to be present in people who are not ill and that the course and symptoms of an illness are not experienced the same in all individuals. Engel drew the conclusion that psychological, social and cultural factors need to be considered, and if this is the case within medicine then it is even more crucial for psychiatry. Engel therefore proposed a Biopsychosocial Model that takes into account the patient’s social world and their own perceptions, as well as biology, and sees the person and not just the illness. Current research into the etiology of EDs proposes a range of casual factors and relationships between them. The general consensus on the approach to integrating these factors is the Biopsychosocial Model (Polivy & Herman, 2002).

While accepting the value of the Biopsychosocial Model in moving away from a biological reductionist approach to medicine, Ghaemi (2009) raised concerns over the vagueness of the model due to its vast expanse, and the lack of guidance on how to prioritise the many factors in practice. When considering the complexity of EDs and the huge range of causal factors put forward in the literature, taking a biopsychosocial approach would have been too large a scope to cover within the frame of this thesis. It has been suggested that scientific advances are enabling research into genetics and biology to progress at a faster rate than less easily measurable factors, such as environmental influences (Striegel-Moore & Bulik, 2007). Furthermore, aspects of individual human biology are often something that the person themselves is not aware of or able to articulate in comparison to their thoughts and experiences. Therefore, this thesis is underpinned by a psychosocial theoretical framework.

Based on existing research and the ontological position, this project was carried out under the assumption that it would be too simplistic to think that each causal factor acts in isolation. Individuals do not all act in the same way when in the same social environment, and an individual does not consistently behave in the same way regardless of their environment. These inconsistencies suggest an interplay between psychological factors and social influence, in line with the critical realist assumption that experiences can shape perspectives and therefore behaviours. Keel and Forney (2013) refer to homophily, the tendency for those who share similar traits to be more likely to socialise together, as well as how personality traits shape responses to social stimuli, in their description of psychosocial risk factors in EDs. Although it is possible to study each factor separately, the psychosocial theoretical framework accepts these factors can influence each other and their presence is often correlated. Hollway and Jefferson (2013) explain in their psychosocial approach that we cannot hope to understand a subject's inner world without knowing what their experiences have been, and that we cannot understand their experiences in the world without having some knowledge of how their inner world shapes those experiences. It is therefore important to recognise interrelations to generate a more accurate picture of complex disorders such as EDs, and to better understand the experiences of participants.

The psychosocial model guided the development of the survey items in the present quantitative study, ensuring multiple social and psychological factors were included. The qualitative study in the present thesis enabled participants to describe a combination of psychological and social factors that they perceived to be important and often intertwined, and the method of data analysis ensured any interrelations between factors were not lost by breaking the data down into individual factors. During the mixed methods integration, the findings from the qualitative study were able to provide further context to the quantitative results, in which correlations between variables were also tested.

2.4 Eating Disorders

2.4.1 What is an Eating Disorder?

The umbrella term of 'eating disorders' refers to an abnormal attitude towards food, shape or weight that leads to unhealthy changes in eating habits. These habits include numerous behaviours that can vary considerably but all of which can have a damaging impact upon health. This has resulted in several different types of EDs being classified. The most well-known types of EDs, and those which will be considered within this thesis, are anorexia nervosa (AN), bulimia nervosa (BN) and binge-eating disorder (BED) (NHS, 2015). Behaviours similar to those that would be considered symptoms of an ED, such as self-starvation, have been documented since the Middle Ages but these behaviours are thought to have been linked to beliefs around spirituality and religion. In the 18th century industrialisation began a change in social norms, with body image and feminine ideals beginning to be emphasised, and by the 19th century food-refusal was increasingly being seen as linked to psychiatry (Dell'Osso et al., 2016). The first clinical descriptions of anorexia nervosa were provided by two distinguished physicians, Sir William W. Gull and Professor Charles Lasègue, simultaneously in 1873 (Silverman, 1997). However, it was not until the late 1960s that anorexia nervosa became substantially more prevalent (Polivy & Herman, 2002). Bulimia nervosa did not emerge as a disorder in its own right until the late 1970s (Polivy & Herman, 2002; Russell, 1979) and binge eating disorder was a much later addition, not being considered as a specific diagnosis until the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) (American Psychiatric Association, 2013).

The DSM-5 (American Psychiatric Association, 2013) sets out the diagnostic criteria for each disorder with some clear distinctions. The DSM-5 also includes criteria for the diagnosis of pica, rumination disorder, avoidant/restrictive food intake disorder (ARFID), and unspecified feeding or eating disorder, all of which were not considered in this thesis. The diagnostic criteria for AN, BN and BED, as set out by the DSM-5, are described below.

2.4.2 Anorexia Nervosa

A defining feature of AN is being significantly underweight, requiring a body mass index (BMI) of less than 85% of the median for age and gender for diagnosis. There also needs to be a persisting fear of weight gain, and using weight and shape as one of the key means of self-evaluation . Two subtypes of AN are set out to distinguish between those who binge and purge (AN-BP), and those who are restrictive (AN-R). There are some similarities with BN in the behaviours of some people diagnosed with AN (those with AN-BP).

2.4.3 Bulimia Nervosa

BN involves having at least four uncontrollable binge-eating episodes (eating a large amount of food within a short time frame, with a sense of loss of control) and at least four episodes of compensatory behaviours (e.g. purging: self-induced vomiting, misuse of laxatives, diuretics, diet pills, or non-purging behaviours: excessive exercise, fasting) per month for at least three months. As with AN, weight and shape are one of the key means of self-evaluation , however being significantly underweight is not necessary for diagnosis.

2.4.4 Binge Eating Disorder

BED only became a recognised disorder in its own right in the DSM-5 following reviews conducted in 2009 and a proposal that was well supported (Keel et al., 2011). A BED diagnosis requires at least four uncontrollable binge-eating episodes each month for at least three months, and less than one compensatory act per month throughout this time. Other central features include eating when full or not hungry, and experiencing a high level of distress, guilt, embarrassment or disgust about binge eating.

2.4.5 Subthreshold Eating Disorders

The previous version of the DSM, the DSM-IV, included a category called eating disorder not otherwise specified (EDNOS). This referred to someone who has symptoms of an ED that are considered to be clinically severe but do not meet the specific diagnostic criteria for AN, BN or BED. EDNOS previously accounted for 60% of outpatients diagnosed (Fairburn & Bohn, 2005). This thesis, however, did not consider EDNOS due to the wide range of symptoms that are included, making comparison as a single group to the other diagnoses difficult. The DSM-5 replaced the EDNOS category with other specified feeding and eating disorders (OSFED), which includes: atypical AN (at least a 10% weight reduction rather than BMI), subthreshold BN (at least two binge-eating episodes and compensatory behaviours per month for at least three months, or six in a shorter time frame), and subthreshold BED (at least two binge-eating episodes per month for at least three months, or six in a shorter time frame). OSFED also includes purging disorder and night eating syndrome, which were not considered in this thesis.

The inclusion of separate subthreshold categories, each with different criteria, enables most people to receive a named diagnosis, recognising the severity of these disorders and the impact they can have. Comparing full and subthreshold BN, Chapa et al. (2018) concluded that BN was not more clinically severe or impairing than subthreshold BN and both require treating to the same intensity. Similarly, atypical AN has been found to closely resemble threshold AN and to have a comparable risk of serious medical consequences and complications (Kerem et al., 2017; McIntosh et al., 2004). Research into subthreshold BED is more limited, but comparing obese patients accessing bariatric surgery in relation to anxiety, depression and neuroticism, those with subthreshold BED were deemed to be aligned more closely with BED than the non-ED group (Dahl et al., 2012). These findings in relation to AN, BN and BED demonstrate the relevance of considering experiences of subthreshold EDs.

Creating subcategories has resulted in more specific diagnoses rather than grouping together a range of behaviours. Keel et al. (2011) found improved discrimination between the DSM-5 diagnoses when compared to the DSM-IV, supporting these additions and highlighting the importance in acknowledging the behaviours that differentiate between each diagnosis. People who received their diagnosis prior to 2013, however, may still use the term EDNOS and it is frequently used within the literature to encompass any ED that is not AN or BN, including participants who would now be diagnosed with BED.

2.4.6 Diagnostic Crossover

For people within the first five years of their illness in particular, there is a risk of diagnostic crossover between AN and BN (Tozzi et al., 2005). As well as crossover between diagnoses, there has also been a crossover found within AN subtypes. Eddy et al. (2002) found in a longitudinal study of 136 patients diagnosed with AN that over 62% of participants had crossed from AN-R to AN-BP after eight years. They concluded ANR and ANBP to be different stages throughout the course of AN, rather than different subtypes of the illness. Keel and Brown (2010)'s review of the course of EDs also revealed a crossover from AN to BN, as well as the suggestion that the symptoms of EDNOS often reflect partial remission, and constitute the course of an ED. This demonstrates the complexity of these disorders, the sometimes fluid nature of the symptoms and, therefore, the specialist knowledge and understanding required to diagnose and treat them.

2.5 Relevance

2.5.1 Epidemiology

EDs are prevalent across all racial and ethnic groups (Rodgers et al., 2018). The prevalence of EDs is reported to be disproportionately higher in more affluent countries and cultures, and are therefore expected to increase in line with global economic development and Westernisation (Erskine et al., 2016). A review of the literature on the epidemiology of EDs estimated that there are 8 cases of AN and 12 cases of BN per 100,000 population each year (Hoek & van Hoeken, 2003). Despite only being a small percentage, based on a world population of 7.3 billion that equates to almost 1.5 million cases of these illnesses every year. Keski-Rahkonen and Mustelin (2016) conducted a more recent review of European studies and concluded a lifetime prevalence for women of AN of up to 4% and <1-2% for BN, suggesting a slight decline in BN but an increase in AN. In addition, Hudson et al. (2007)

estimated the lifetime prevalence of BED to be 3.5% for women and 2% for men. There are few New Zealand epidemiology studies. The best estimate comes from the New Zealand Mental Health Survey, which found an estimated lifetime prevalence of an ED (only AN and BN were assessed and not distinguished) of 1.7% for the general population within New Zealand (Oakley Browne et al., 2006).

Not only are EDs unevenly distributed across the globe but women are more likely to receive a diagnosis than men (Udo & Grilo, 2018). It is estimated that girls aged 15 to 19 years old represent 40% of AN diagnoses (Hoek & van Hoeken, 2003). Keski-Rahkonen et al. (2007) reported an incidence rate of 270 per 100,000 for AN females in that age group. Adolescent females are also at a greater risk of BN, with an incidence of 300 per 100,000 reported for girls aged 16 to 20 years old (Keski-Rahkonen et al., 2009). Although biology plays a role in sex differences, the possibility of psychosocial factors influencing the increased vulnerability for adolescent females cannot be disregarded (Keel & Forney, 2013). Furthermore, gender differences have been found in body image, weight perceptions and the influence of weight on self-evaluations (Calogero & Thompson, 2010; Grover et al., 2002). Due to the higher prevalence of EDs in females, and the potential for gender differences in psychosocial influences, the present research focuses solely on the perceptions of females.

Building an accurate picture of the global scale of EDs is difficult. Not everyone seeks treatment or even accepts or discloses they have an illness, which means community studies and the use of medical records are likely to underestimate the prevalence (Smink et al., 2012). It is suggested that people with AN often only enter treatment due to those closest to them seeking help on their behalf, and as people with BN can be a healthy weight the illness can often go unnoticed (Polivy & Herman, 2002). Mental health literacy around EDs may provide a barrier for help seeking due to a lack of knowledge and the existence of stigma (Bullivant et al., 2020). It is therefore anticipated that the true extent of EDs is much higher than recorded statistics suggest.

2.5.2 Impacts of Eating Disorders

EDs are very serious mental illnesses. With the possible exception of the recent opioid epidemic in the USA, AN is reported to have the highest mortality rate of any psychiatric disorder (NIMH, 2016). The crude mortality rate for AN is estimated at 5% (Steinhausen, 2008). A meta-analysis determined annual mortality rates (per 1,000) of 5.1 for AN, 1.7 for BN and 3.3 for EDNOS (Arcelus et al., 2011). As well as an increased risk of premature death from malnutrition, complications from substance abuse and suicide (Herzog et al., 2000), additional health impacts include, but are not limited to, hypokalaemia, hypomagnesaemia, osteoporosis, infertility, dysfunction in the endocrine system, cardiovascular abnormalities, esophageal strictures and rupture, pancreatitis, perimylolysis (dental erosion), anemia, leukopenia and ulcers (Pomeroy & Mitchell, 2002). Many of these consequences can be, or can act as a catalyst to other illnesses that can be, serious or even fatal.

2.5.3 Comorbidity

EDs are highly comorbid with other mental health illnesses. Through a US National Comorbidity Survey, Hudson et al. (2007) found that of 2980 respondents with an ED, 56.2% of those with AN, 94.5% of those with BN and 78.9% of those with BED met the criteria for at least one other DSM-IV disorder. They included mood, anxiety, substance abuse and impulse control disorders. There have been some differences proposed between diagnostic subtypes. Blinder et al. (2006) assessed 2436 female ED inpatients and found 97% demonstrated a comorbid disorder, with 94% evidencing a mood disorder, mainly depression. They also found alcohol and polysubstance abuse/dependence to be more likely in BN, and obsessive-compulsive disorder (OCD) and schizophrenia/other psychoses to be more likely in AN. These findings align with those by Jordan et al. (2008), who found a high prevalence of anxiety across AN, BN and depression, but specific associations between AN and OCD, and BN and psychoactive substance use disorders. Comorbidity, especially with alcohol abuse, has been suggested to increase the mortality risk in AN (Button et al., 2010; Keel et al., 2003). Although cause and effect cannot be confirmed, the high level of comorbidity in EDs needs to considered due to the potential to increase the severity of the consequences and the complexity and response to treatment.

2.5.4 Treatment of Eating Disorders

As with the prevalence of EDs, it is difficult to determine the proportion who access specialist treatment, but a review of literature into treatment seeking behaviours estimated that it is around 23.2% (Hart et al., 2011). Stigma and shame, denial/failure to perceive the severity, cost, practical access issues (transport, childcare, time), fear of losing control or change, negative attitudes towards treatment, lack of support or encouragement, and lack of knowledge of treatment, have been determined as barriers to accessing treatment (Ali et al., 2017). Despite low access rates, there are a range of different treatments available for EDs. The type of treatment received can vary depending on age and diagnosis, as well as service provider preferences. There are multiple different guidelines and recommendations for treatment, varying dependent on diagnosis. Key guidelines from the Royal Australian and New Zealand College of Psychiatrists (RANZCP) (Hay et al., 2014), National Institute for Health and Care Excellence [NICE] (2017), and American Psychiatric Association (2006) (APA) for the treatment of AN, BN and BED are set out below.

For AN, all three sets of guidelines state that weight gain is the initial goal to ensure medical stabilisation and reduce cognitive impairments resulting from starvation that may limit the effectiveness of psychological treatments. For the treatment of adults with AN, NICE guidelines recommend either ED-focused cognitive behavioural therapy (CBT), Maudsley Anorexia Nervosa Treatment for Adults (MANTRA) or specialist supportive clinical management (SSCM). If these options are ineffective then ED-focused focal psychodynamic therapy (FPT) is suggested. Similarly, APA recommends CBT, individual or group IPT or psychodynamically oriented therapy. For children and young people under 18 years, however, all three guidelines recommend family-based therapy (FBT) as the primary recommendation, with CBT or adolescent-focused psychotherapy (both of which include a number of family sessions) if FBT is ineffective.

For adults with BN, APA and RANZCP recommend CBT in the first instance, with IPT as a secondary option. NICE, however, recommends a bulimia-nervosa-focused guided self-help programme, with CBT as a secondary option. For children and young people, similarly to AN, FBT is the primary recommendation, by both NICE and APA, with CBT recommended if FBT is ineffective.

For BED, the NICE treatment guidelines remain the same for children, young people, and adults; a binge-eating-disorder-focused guided self-help programme is recommended primarily, with group CBT as a secondary option, and individual CBT to be considered in the final instance. APA and RANZCP, however, both recommend CBT in the first instance and IPT or dialectical behavioural therapy (DBT) as secondary options. While guidelines from NICE and APA show some variation between BN and BED, the RANZCP guidelines consider treatments for BN and BED alongside each other, as EDs that can both occur in individuals who are not underweight.

Further psychological treatments for EDs include interpersonal psychotherapy, dialectical behaviour therapy, often for BN and BED (Hay et al., 2014), and cognitive remediation therapy (CRT), cognitive bias modification, exposure therapy, inhibition training, particularly for enduring AN (Treasure et al., 2015). Pharmacological treatments and dietary counselling are recommended to be used only when alongside psychological treatments and more frequently for comorbid disorders than EDs alone (Hay et al., 2014; National Institute for Health and Care Excellence [NICE], 2017). Consistent with a psychosocial framework, the term treatment used in the present thesis refers to all forms of psychological therapy, as opposed to pharmacological treatments. Although treatment recommendations continue to be published, the type of therapy and the way in which it is delivered may depend on the therapist and their beliefs, knowledge and experience rather than evidence-based treatment guidelines (Waller, 2016b). Outcomes for different types of therapy and factors that may influence treatment efficacy are reviewed in the next chapter, but there is a broad consensus that relapse rates following discharge from treatment are substantial (Hay et al., 2014).

2.5.5 Treatment of Eating Disorders in New Zealand

New Zealand uses a hub and spoke model for the delivery of services to treat EDs. There are three specialist regional ED services based in Auckland, Wellington and Christchurch (the hubs), who are funded by the government to provide services, as well as training, supervision and support to local services in nearby district health board areas (the spokes) (Lawson & Dunnachie, 2017). The Auckland hub covers the northern half of the North Island, the Wellington hub covers the southern part of the North Island, and the Christchurch hub covers the South Island. New Zealand's Ministry for Health requires all district health boards to have an ED intervention in their Annual District Plan, but types of treatment, and ways in which treatment is delivered, can vary depending on the location (Lawson & Dunnachie, 2017).

2.5.6 Definitions of Key Constructs

2.5.6.1 Causal Factor

The term ‘cause’ has been used in a variety of ways, sometimes inconsistently referring to differing constructs (Kraemer et al., 1997). Entering into the philosophical debate about the nature of causality is out of the scope of this thesis. Following a review of the discussions on the topic, Susser (1991) defines a cause from an epidemiological standpoint as something that makes a difference to a health outcome. Within this definition, it is accepted that the presence of multiple factors may be required before achieving sufficiency to affect an outcome, supporting models of multiple and contributory causes. In the present thesis, the term causal factor refers to any factor that contributes to the onset of an ED, including in the presence of or through an interaction with other factors. A review of current literature on causal factors in EDs is provided in the next chapter, Chapter 3.

2.5.6.2 Maintenance Factors

Stice (2002) defined maintenance factors in EDs as the factors that predict the persistence of symptoms versus remission. Maintenance factors in the present study therefore refer to factors that explain why ED-related behaviours continue to persist over time. Current literature on the maintenance of EDs is presented in Chapter 3.

2.5.6.3 Recovery

It is widely recognised that there is no clear definition of recovery for EDs (Bardone-Cone et al., 2018; Jarman & Walsh, 1999; Murray, 2020). Inconsistencies in the definition of recovery demonstrate the importance in considering the author’s definition of recovery when reviewing the literature. A critical examination of the literature revealed ways of determining recovery included weight restoration, no longer binge eating and purging, changes in preoccupation with food and reductions in negative body image, and the clients’ views on recovery were often missing (Jarman & Walsh, 1999). Following a recent review, Murray

(2020) emphasised the need to consider client perspectives when determining what is meant by the term recovery as their views can include additional dimensions. For instance, when ex-patients were presented with a list of potential recovery criteria, they rated weight, eating behaviours, psychological, social and emotional criteria as important in evaluating recovery, and stated that the list needed to be more expansive (Noordenbos & Seubring, 2006). Darcy et al. (2010) used semi-structured interviews with women with a history of AN, a method which allowed participants to elaborate on their responses, and found a substantial proportion detailed multiple factors beyond ED symptoms. Furthermore, definitions of recovery have been found to vary between therapists and patients (Noordenbos, 2011) as well between individual patients (Darcy et al., 2010).

Research suggests that many people who have experienced an ED consider recovery to be ongoing. Some people considered themselves to be within the recovery process (Federici & Kaplan, 2008), and others expressed ambivalence around the notion of full recovery (Darcy et al., 2010). It therefore appears that many people may feel uncomfortable stating that they are ‘fully recovered’ despite meeting the medical criteria. Jacob (2015) proposed a new recovery model of mental illness in which the focus is on the ability for individuals to live a meaningful life where they can realise goals and dreams even with residual symptoms, rather than trying to return to premorbid functioning. Whilst this model was for the field of psychiatry as a whole, it appears to reflect the views of those participants in the previously described research who felt the concept of full recovery as defined by some physicians is unattainable. As previously established, the focus of the present thesis is upon the participant’s perspective and their experiences. In line with the aims of the PhD, recovery status here was self-reported by the participant, thus being recovered refers to participants who perceived themselves to be recovered or significantly improved. However, as the literature demonstrates that people with lived experience of an ED have varying definitions of recovery, the term ‘recovery’ will likely have differing meanings between participants, so a single definition for use in this thesis cannot be provided. Further detail on how recovery status was ascertained is provided later on in the thesis.

2.6 Concluding Remarks

This thesis was carried out under a critical realist ontology, using a mixed methods approach, with the assumption that there is a reality independent of human existence but social interactions and experiences can shape human knowledge and perceptions of this reality. The psychosocial theoretical framework that underpins this thesis follows this assumption, considering both a person’s inherent psychological traits and their social environment to be equally important and often linked when trying to understand why a person behaves in a certain way.

EDs are illnesses that involve unhealthy attitudes and behaviours around food. AN, BN and BED are highly comorbid with other psychiatric disorders and can have serious or even fatal consequences. It is estimated around 1.7% of the New Zealand population will experience an ED, with females at a higher risk of diagnosis than males. Psychological treatments for EDs are varied, with diagnostic differences in the recommendations. The present thesis explores participants’ perceptions of factors that contributed to the onset of an ED (causal factors), factors that explained the persistence of ED-related behaviours (maintenance factors), and factors related to recovery from an ED (a construct self-defined by participants).

CHAPTER THREE: Literature Review on the Etiology, Maintenance, Treatment and Recovery of Eating Disorders

3.1 Introduction

As established in the previous chapter, EDs are serious mental health illnesses that can have grave consequences. The last 30 years has seen an increase in the amount of research directed towards understanding what causes and maintains EDs, and how they can be alleviated. There are similarities and differences among the three types of ED diagnosis that were focused upon in this thesis (AN, BN and BED). The literature to date examining the etiology of EDs suggest a wide range of biological, social and psychological causal and maintenance factors, with some diagnostic variations. It has been proposed that the etiology of EDs may be best explained through a biopsychosocial model, suggesting that an interaction between genetics, environment and personality may be central (le Grange, 2016), demonstrating the complexity and potential interaction of etiological factors. There are also diagnostic variations in the most frequently used forms of treatment. Research has been conducted investigating the efficacy of different types of treatment for EDs, as well as factors within a particular treatment programme that may influence the outcome, which will be discussed later in this chapter.

The purpose of this chapter is to provide a comprehensive review of the current literature on the etiology, maintenance, treatment and recovery of EDs. Throughout the chapter a distinction is made between the results of studies that applied quantitative methods and those that used qualitative methods to elicit the views of people with lived experience of an ED. A comparison of the different findings from quantitative and qualitative studies is made. The chapter firstly reviews and describes current research investigating the etiology of EDs, including EDs in general or AN, BN or BED specifically. Despite the psychosocial framework under which this PhD was conducted, biological factors are also presented here for completeness. Causal factors identified in the literature are each set out separately for ease of discussion, alluding to relationships established between these factors and acknowledging that they cannot be viewed in isolation. Next, the existing literature that focused on the effectiveness of treatment is reviewed. Finally, the gaps in the literature that need to be addressed are established, which leads to the aims and objectives of this PhD.

3.2 Etiology

Consistent with the research question that sought to explore all factors perceived to have influenced the onset of the participants' ED, a wide range of causal factors commonly cited within the literature are presented here. Further, any diagnostic variations in the literature are also identified.

3.2.1 Biological Factors

There is evidence that EDs may be hereditary, with genetics predisposing an individual to developing one. Biosocial theories suggest that EDs may be linked to the response to developmental changes, or levels of activity in certain neurological pathways may determine behaviour when faced with social stimuli. A number of quantitative studies have sought to investigate biological factors.

3.2.1.1 Genetics

Firstly, evidence provided through family and twin studies suggests that genetics are a contributing factor (Crisp et al., 1985; Himmerich et al., 2019; Lilenfeld et al., 1998; Wade et al., 2000), possibly more so for BN than AN (Bulik et al., 2000b), although the majority of studies have been conducted with AN (Himmerich et al., 2019). The influence of a shared environment, however, cannot be disregarded. In an attempt to overcome this methodological weakness, Klump et al. (2009) compared biological and adoptive siblings, and found a higher covariance in the biological siblings, again leading to the inference that genes have an influence in the development of an ED. However, due to the need to have a sample size large enough to draw significant conclusions, the study measured disordered eating behaviours through a survey for the general population not clinically diagnosed EDs. More recently, Duncan et al. (2017) identified, for the first time, a genome-wide significant locus associated with AN, further substantiating previous evidence. A large scale study consisting of 16,992 cases of AN and 55,525 controls identified genetic correlations with metabolic and anthropometric traits, proposing the that the illness should be considered as ‘metabo-psychiatric’ (Watson et al., 2019).

Although recognising that genetics may have a role in the development of an ED is important, there is an acceptance that the interaction with social and psychological influences is at least equally important and needs to be understood. Reviewing current research into genetics, epigenetics, gene expression, nutritional genomics, gene–gene interactions and microbiomes, Himmerich et al. (2019) derived a pathophysiological model of EDs. The model incorporates gut microbiota, the metabolic and endocrine system, the immune system and regulatory systems in the brain, in addition to social, environmental, and nutritional factors. Furthermore, BMI has also been found to be substantially influenced by genetics (Stunkard et al., 1990). Being overweight has been identified as a potential risk factor for an ED, particularly BED (Fairburn et al., 1998; Hilbert et al., 2014) and BN (Fairburn et al., 1997), due to the social and psychological implications it can have in relation to cultural norms and ideals (Striegel-Moore & Bulik, 2007), which will be discussed later in this chapter.

3.2.1.2 Puberty

Incidences of both AN and BN are known to peak in adolescence, with prevalence at its highest in females aged 15 to 19 years (Keski-Rahkonen et al., 2009; Keski-Rahkonen et al., 2007). It has been theorised by researchers that the biological changes that occur during puberty may have a role. In females, the development of the body away from a thin figure through an increase in adipose tissue could lead to increases in body dissatisfaction and dieting, especially in early menarche when development leads to a different body shape to peers (Stice, 2002). Within community samples of young girls of a similar age, those exhibiting ED symptoms were significantly more advanced in their pubertal development (Killen et al., 1992; Koff & Rierdan, 1993). Two qualitative studies from the patients' perspective found that some participants described the difficulty of going through puberty and the physical changes to their body as contributing to the onset of their AN (Gulliksen et al., 2017; Tozzi et al., 2002). While this suggests puberty may be a factor in EDs, it does not prove that solely the biological changes to the body are responsible. It could be inferred that the social response to these changes, and the psychological implications of this response, has an influence.

It has also been suggested that increased estradiol levels during puberty impacts upon the neural structure, which may activate genetic effects on disordered eating (Klump et al., 2010). However, results are inconsistent, with other studies finding early menarche to be a risk factor for general psychopathology but not EDs specifically (Stice et al., 2001), or to be an influence when in combination with negative parental relationships (Swarr & Richards, 1996) or beginning to date (Smolak et al., 1993). A review concluded that there is little support that early menarche alone is a risk factor for developing an ED, but may be a contributor when occurring alongside other stressors (Stice, 2002). It has been suggested that puberty is linked to increased internalisation of the thin ideal body type (Hermes & Keel,

2003) and body dissatisfaction increases as the body changes away from this perceived ideal shape (Stice et al., 2001). Therefore, it could be construed that, as well as the physical changes that occur during puberty, there is an increased vulnerability to societal pressures during that time which can result in a negative response to pubertal development in some adolescents. These physical and social impacts of puberty may have an interactive as well as direct effect on the onset of an ED.

3.2.1.3 Temperament Dimensions

Cloninger (1986) described three dimensions of personality which he proposed as having a neurobiological basis that determine the way in which someone reacts to stimuli: novelty seeking (NS), which is connected to dopaminergic activity and actively responding to novel stimuli to pursue reward; harm avoidance (HA), which is linked to serotonergic activity and the inhibition of responses to aversive stimuli to avoid punishment; and reward dependence (RD), which is associated with noradrenergic activity and receiving a positive response to reward-based conditioning stimuli. Later defined as dimensions of temperament (Cloninger et al., 1993), clinical studies have revealed some differences in temperament between ED patients and the general population, and between ED types.

NS has been reported to be high in BN but low in AN (Atiye et al., 2015; Fassino et al., 2002; Kleifield et al., 1994; Klump et al., 2000), suggesting AN may be linked to a more organised and obsessive personality and BN to be more likely in someone who is impulsive and enjoys exhilaration (Kleifield et al., 1994). High HA appears to be a contributing factor for developing either ED (Brewerton et al., 1993; Bulik et al., 2000; Diaz-Marsa et al., 2000; Fassino et al., 2002; Klump et al., 2000; Klump et al., 2004), with the healthy population having a much lower level (Kleifield et al., 1994), but restrictive AN seeming to have a lower level than any disorder with an element of BN (Atiye et al., 2015; Bulik et al., 1995; Diaz-

Marsa et al., 2000; Kleifield et al., 1994). It has also been found that restrictive and purging-only AN have a greater level of persistence, previously a sub scale of RD but more recently separated out, than the general population (Dalle Grave et al., 2007; Diaz-Marsa et al., 2000; Fassino et al., 2002; Klump et al., 2000). A review determined individuals with BN have also been found to have higher levels of persistence than the general population, although not as high as AN, but those with BED have not (Atiye et al., 2015).

RD, on the other hand, has yielded much more contradictory results. One study reported that patients with BN had lower levels of RD than healthy controls (Kleifield et al., 1994), and another found women with restrictive and purging only AN had lower levels of RD but not the bulimic subtype (Klump et al., 2000). Furthermore, women with AN in another sample were found to have higher levels of RD than women with comorbid AN and BN, but not BN alone (Bulik et al., 1995). Another study found no diagnostic differences (Brewerton et al., 1993). Given these complex and mixed findings, further investigation into this dimension of temperament is needed.

Evidence suggests dimensions of temperament differ between people suffering from different ED types and the healthy population, implying certain dimensions contribute to the onset of an ED. Temperament determines how one responds to stimuli, therefore these factors may only be influential for people who face certain social stimuli. It is difficult however to establish cause and effect as the scales in these studies were administered after diagnosis. It cannot be proven that results would have been the same prior to the development of their ED, as research has found that the temperament scale responses are not stable pre and post ED treatment (Agüera et al., 2012; Dalle Grave et al., 2007).

3.2.2 Social Factors

The environment in which a person is raised and lives has been associated with the etiology of EDs in a number of ways, including their social interaction with others. These social and environmental factors include relationships with parents and peers, aspects of the culture lived in that are often portrayed or exacerbated through the media, suffering trauma or abuse, and experiencing high levels of stress.

3.2.2.1 Parenting

As parents are usually the first attachment made and social interaction experienced, the parental role in the development of an ED has been the focus of numerous studies. Quantitative data analyses using clinical ED samples found high criticism of weight and body shape, high expectations and minimal levels of affection from parents in people with BN and BED compared with healthy controls (Fairburn et al., 1998). Low perceived levels of maternal and paternal care, and perceived overprotectiveness, have been linked with AN and BN (Calam et al., 1990). A relationship between overprotectiveness and disordered eating was also found in a community sample of adolescent females (Abebe et al., 2014). Yet the influence of family interaction patterns has also been disputed (Harding & Lachenmeyer, 1986; Waller, 1992). Whilst a review of the literature found dysfunctional patterns of communication in families of individuals with AN to be a commonality (McIntosh et al., 2000), it is difficult to differentiate between cause and effect. McIntosh et al. (2000) discussed how coping with the impacts of the illness will put pressure on the family unit, which in turn may increase the level of dysfunction. A more recent review concluded that, while family-related factors may have a small impact on the onset and maintenance of EDs, evidence does not support any familial influences as being primary or distinct causes of AN or BN (le Grange et al., 2010).

In qualitative research asking those with AN and BN what they believed caused their ED, it was found that participants reported the following causal factors: having controlling, overinvolved and intrusive parents (Hsu et al., 1992; Rossotto et al., 1996; Tozzi et al., 2002), having a poor or difficult relationship with parents (Hsu et al., 1992; Lacey et al., 1986; Rossotto et al., 1996), and having strict parents with high expectations (Redenbach & Lawler, 2003; Tozzi et al., 2002). Overprotectiveness was described by some participants with AN (Beresin et al., 1989; Hsu et al., 1992). One study interviewing women with BN found some had experienced pressure directly from their parents to be thin or lose weight (Rossotto et al., 1996). Although these findings do support the evidence from the quantitative literature, a number of qualitative studies from the perspective of those with AN and BN identified additional contributing factors such as parental marital conflict (Beresin et al., 1989; Lacey et al., 1986; Tozzi et al., 2002) and witnessing parents or other family members dieting or having issues with food (Rossotto et al., 1996; Tozzi et al., 2002).

3.2.2.2 Peer Relationships

With the peak age of onset for EDs being during adolescence, the relationship with peers is also considered to be important as this is the point at which the main social interaction tends to change from family to friends, and romantic relationships begin (Bulik, 2002). High levels of peer competition has been associated with high body dissatisfaction in adolescent girls (Fergusson et al., 2014). Community based quantitative research has found levels of body concerns, dietary restraint and weight loss behaviours to have a greater similarity within friendships groups than between them, but not binge eating (Paxton et al., 1999), suggesting peer influence may be greater in AN rather than BN or BED. High levels of self-reported peer pressure was a significant predictor of binge eating and subsequent compensatory behaviours in another nonclinical sample (Young et al., 2001). In support of these quantitative findings, qualitative studies found that some participants believed peer pressure was partly responsible for the onset of their AN or BN (Granek, 2007; Rossotto et al., 1996).

As well as friendship groups and peer pressure, quantitative research has found that negative relationships with peers may have an influence. A meta-analysis found people with an ED were up to three times more likely than healthy controls to have been bullied, particularly about their appearance, with a stronger association in BN and BED than AN (Lie et al., 2019). Being teased by peers about weight and appearance during childhood was found to be common in a sample of ED patients and was associated with higher body dissatisfaction and feelings of shame in adulthood. This led to a psychosocial model that proposed being teased by peers increases levels of shame which generates pathological body dissatisfaction that manifests itself into an ED (Sweetingham & Waller, 2008). The model is substantiated by research with both the general population (Eisenberg et al., 2003) and women who met criteria for BED (Jackson et al., 2000), which found teasing about weight and shape was associated with lower self-esteem and lower body satisfaction. With the increase in use of social media, applications such as Facebook, Twitter and Instagram appear to be popular platforms for cyberbullying of adolescents, with peers the most common perpetrators (Whittaker & Kowalski, 2015). Cyber victimisation has been found to be linked to low appearance evaluations and ED psychopathology (Marco & Tormo-Irun, 2018). Furthermore, social media use has been positively correlated with body dissatisfaction (Tiggemann & Slater, 2013, 2017) and disordered eating behaviours (Wilksch et al., 2020). Media influence is discussed in more detail in the next section (3.2.2.3).

Through direct interviews, participants with AN also attributed poor relationships and bullying from peers as causal factors (Hsu et al., 1992; Lacey et al., 1986; Nilsson et al., 2007). It appears that peer victimisation, especially aimed at body weight and appearance, can have a negative psychological impact which then increases vulnerability to illnesses such as EDs. In addition, women with a history of an ED described a number of other perceived causal factors that linked to the role of peer relationships, including a lack of a sense of belonging (Patching & Lawler, 2009), feeling lonely and having few friends (Gulliksen et al., 2017). The connection between poor peer relationships and EDs may be linked to a negative impact on self-esteem or a lack of social support to help cope with psychological distress.

3.2.2.3 Media Influence

Alongside direct social interactions, the wider environment and sociocultural factors are believed to have an influence on the development of EDs. EDs are more likely to occur in countries where there is no shortage of food available yet slimness is idealised and the media is saturated with the message that thinness is associated with attractiveness and success. It is claimed that the internalisation of this message disrupts eating patterns (Polivy & Herman, 2004). A comprehensive meta-analysis of 77 studies concluded that thin-ideal media exposure was linked to women's internalisation of thin as the ideal body, body dissatisfaction, and a greater frequency of disturbed eating attitudes and behaviours (Grabe et al., 2008). Using surveys completed by 1,087 female adolescents, Tiggemann and Slater (2013) found that internet exposure was correlated with internalisation of the thin-ideal body type, body surveillance and drive for thinness.

Furthermore, a significant positive correlation has been found between media exposure and both disturbed eating attitudes and gender-role endorsement; gender-role endorsement was associated with the internalisation of the thin-ideal, which predicted body dissatisfaction, which, in turn, was associated with disturbed eating attitudes (Stice et al., 1994). These findings indicate that the effects of media consumption are complex and involve a number of interconnected elements. Furthermore, delivery of a media literacy programme to adolescents was found to reduce shape and weight concerns, eating concerns, dieting and body dissatisfaction, suggesting that increasing media literacy may reduce the risk of an ED (Wilksch & Wade, 2009; Wilksch et al., 2015).

As described in the previous section, the use of social media use may also contribute to an increased risk of developing an ED. A review concluded that the use of social networking sites was correlated with body image concerns and disordered eating; a relationship moderated by internalisation of the thin-ideal and a tendency to make appearance based comparisons (Holland & Tiggemann, 2016). Research has also found the number of different social media platforms used was associated with the level of disordered eating behaviours and cognitions (Wilksch et al., 2020).

Nevertheless, as argued by Polivy and Herman (2002), this does not explain why the majority of the population exposed to the same sociocultural factors do not go on to develop an ED, and so there must also be individual vulnerabilities involved. Also, these studies have focused on changes in attitudes and behaviours of the general population rather than analysing media consumption of people with an ED diagnosis. None of the few qualitative studies that interviewed participants with an ED diagnosis found media portrayals of the ideal body stereotype or the focus upon the appearance of women to be perceived as causes of their ED. Participants in several studies did, however, discuss the way in which the media ameliorated the maintenance of their ED, by portrayals of the thin ideal reinforcing their behaviour (Dignon et al., 2006; Redenbach & Lawler, 2003). This qualitative finding provides a different perspective that quantitative research appears to have overlooked.

As well as the western media promoting a thin ideal body image, obesity is also portrayed extremely negatively, with overweight characters being deemed as less important, unable to find a romantic partner, less competent, and an object of humour (Greenberg et al., 2003). Fat shaming videos accompanied by critical comments are prevalent across YouTube

(Hussin et al., 2011). The emergence of social media has provided a platform to intensify this message, with a wealth of 'fat jokes' being shared and weight-based cyber bullying reinforcing negative stereotypes (Chou et al., 2014). The internalisation of this message is evident even in children, with Latner et al. (2007) finding a significant association between media exposure and stigmatised attitudes and dislike of obese children in 10 – 13 year olds. This suggests that people not only strive to have the thin ideal body size, but it remains socially acceptable to bully those who are overweight, which can have significant psychological implications, particularly for young people and those already at a high risk of developing an ED.

3.2.2.4 Trauma History

Each person's life is a unique constellation of experiences, events and incidents, unfortunately not all of which are positive. Both quantitative and qualitative data suggests a link between experiencing trauma and developing a subsequent ED. In Tagay et al. (2010)'s study of ED patients, 63.3% with AN and 57.7% with BN reported experiencing at least one traumatic event.

A number of quantitative studies have suggested suffering sexual trauma is significantly associated with an ED diagnosis (Fairburn et al., 1998; Forman-Hoffman et al., 2012), particularly child sexual abuse (CSA) (Waller, 1998) and repeated sexual abuse (Welch & Fairburn, 1994). Women who experienced rape were found to be more likely to meet criteria for an ED than women who experienced a non-sexual trauma, although the particular ED diagnosis was not specified (Faravelli et al., 2004). Evidence indicates that higher rates of sexual abuse has been found in disorders with a bulimic component (Fairburn et al., 1998; Waller, 1991, 1993). Significantly more BN symptoms, but not AN symptoms, were self-reported by adolescents who had experienced CSA than a healthy control group (Li et al., 2018). Binge eating has been found to increase if the abuse occurred before the age of 14 and/or involved the use of force, and binge eating with purging increasing with intrafamilial abuse (Waller, 1992b). In addition to CSA, a meta-analysis found childhood maltreatment (comprising of sexual, physical and emotional abuse) was significantly higher across ED diagnoses than both the healthy and psychiatric control groups (Molendijk et al., 2016). Another review and meta-analysis found BN and BED to be associated with childhood sexual, physical and emotional abuse, but AN was only significantly associated with physical abuse (Caslini et al., 2016). Evidence demonstrates therefore that it may not be specifically sexual trauma that can contribute to the onset of an ED.

Rorty et al. (1994) found a greater percentage of participants with past or current BN had experienced CSA than healthy controls, but it was not a significant difference. They did however find physical, psychological and multiple forms of abuse to be of significantly greater prevalence. This was even the case when harsh physical punishment was suffered that the researchers deemed as abuse, but the participant did not perceive it as such (Rorty et al., 1995), suggesting that clients may not always recognise the harm an incident has subconsciously caused them. Without differentiating ED type, physical abuse alone and both physical and sexual abuse during childhood were found to increase the likelihood of ED symptoms and diagnosis, but not sexual abuse alone (Rayworth et al., 2004), demonstrating the complexity of trauma as a causal factor. Physical and sexual abuse, along with bullying by peers, have also been found to be significantly more common in women with BED than the healthy population (Striegel-Moore et al., 2002).

Striegel-Moore et al. (2002) found some differences based on ethnicity, with discrimination associated with BED in white women but not black women. The authors propose this may be due to differences in experiences of discrimination, with white women reporting a focus on physical features and black women reporting discrimination based on their membership of an ethnic minority group. Reviewing the literature, Brewerton (2007) concluded that any experience at any age that has the potential to induce post-traumatic stress may be related to an ED, especially an ED with a bulimic component.

Furthermore, qualitative research found many AN and BN patients believed sexual abuse was at least partly responsible for the onset of their disorder (Dignon et al., 2006; Granek, 2007; Lacey et al., 1986; Rossotto et al., 1996; Tozzi et al., 2002). In another study with women with a history of AN, BN and both diagnoses, several participants identified physical and verbal abuse as causal factors in their ED, although the diagnosis of these individuals was not specified (Patching & Lawler, 2009). There is evidence therefore from qualitative research supporting the conclusions from quantitative data, that experiencing abuse, especially sexual abuse, can be a causal factor for an ED in some individuals.

There are a number of reasons proposed for why abuse appears to be a causal factor in the development of an ED. These potential reasons include restricting food as a form of punishment if the individual feels guilty or to blame (Schwartz & Cohn, 1996), a way of expressing distress through a form of self-harm (McAndrew & Warne, 2005), increased vulnerability to the ED ‘voice’ due to dissociation as a result of the trauma (Pugh et al., 2018), to desexualise the body in an attempt to stop further unwanted sexual attention (Brackenbridge, 1998) and to regain a sense of control over an aspect of their life (Kearney-Cooke & Striegel-Moore, 1994). Waller (1998) established that, within a sample of women with a diagnosed ED, those who had experienced sexual abuse had a more external locus of control than those who had not, meaning they feel they have less power over their own life due to external forces being in control. The correlation between low perceived level of personal control and eating psychopathology increased in strength with the severity of the abuse. The role of control will be discussed in detail later on in this chapter.

3.2.2.5 Life Stressors

In addition to suffering from trauma, evidence also suggests that EDs may be linked to an accumulation of stress from multiple adverse life events. In a community sample, potentially stressful life events, psychological distress, perceived stress and immature defence styles (including dissociation, denial, and projection) were all positively correlated with ED symptoms (Hay & Williams, 2013). Stressful life events were also positively associated with binge eating and extreme weight control behaviours, such as laxative use and induced vomiting, in another community sample of adolescents and young adults (Loth et al., 2008).

Evidence suggests there may be diagnostic differences in the influence of stress on EDs. Speranza et al. (2003) determined their BN sample had suffered more adverse childhood experiences than their AN group, similar to the sexual trauma findings. When measuring the number of stressful life events and an accumulation of stress in clinical samples, Strober (1984) found that patients diagnosed with the bulimic subtype of AN had experienced substantially more stressful events in their life than those with the restrictive subtype. Furthermore, Schmidt et al. (1997) found a considerably larger percentage of both AN and BN patients had experienced at least one major life difficulty in the 12 months prior to onset, compared to a control group of equivalent age and social class. Although there was not a significant difference between AN and BN in the number of major difficulties experienced, there was a difference in the finer detail. Conflict within close relationships with family and friends was the most common area under which stressors were grouped, but those with AN were mainly indirectly involved (such as witnessing marital problems between parents) whereas BN patients were more likely to be directly involved. A review of the literature concluded that although there does appear to be an association between life stress and disordered eating, it is not a necessity for the development of an ED, and there may be a difference in the etiology of AN and BN, evidenced by stress appearing to be a more common factor in BN (Ball & Lee, 2000).

Although the participants in the quantitative studies detailed events that had happened in their past, they did not specify that they believed these events were involved in the onset of their disorder. A qualitative study from the patients' perspective, found all 50 participants with a BN diagnosis detailed an event in the six months prior to onset that they believed to be linked, ranging from sexual conflict, to a bereavement, to a change in occupation (Lacey et al., 1986). Some participants who had recovered from AN also attributed their illness to a stressful experience such as change of school, separation of the family, loss of friends or relationship problems (Beresin et al., 1989; Gulliksen et al., 2017; Tozzi et al., 2002). The qualitative data is therefore consistent with the inferences made from quantitative findings; that people with EDs are likely to have experienced a high level of stress and this may be a causal factor. Yet, this explanation fails to explain why not everyone who suffers some sort of trauma, abuse or accumulation of stress goes on to develop an ED, again suggesting they are multifactorial disorders and points to individual vulnerabilities. Similarly to the findings in relation to trauma, these findings support a diathesis-stress model of EDs, in which traits such as coping strategies may interact with the occurrence of stressful life experiences to increase the likelihood of developing an ED (MacNeil et al., 2012).

3.2.3 Psychological Factors

Consistent with the psychosocial theoretical framework, research suggests a link between social and psychological factors due to the influence psychological traits can have on sensitivity to, responses to and processing of environmental stimuli. For example, some experiences may have a psychological impact, and psychological traits can influence an individual's response to trauma and vulnerability to social pressures.

3.2.3.1 Coping Strategies

Using community samples, Shatford and Evans (1986) found a higher occurrence of stressful life events and daily hassles increased the likelihood of having BN, when in combination with an ineffective coping strategy to mediate the stress. This finding demonstrates an interaction between psychological and social or environmental factors. Coping strategies are the cognitive and behavioural responses to stress used to prevent or manage psychological distress to maintain emotional well-being. The same study conducted on two different samples yielded the same results: avoidant coping, which is avoiding facing the problem, and emotion-focused coping, which is a cognitive response to nullify any emotional distress, were correlated with bulimic symptoms (Shatford & Evans, 1986). Both of these are considered to be ineffective coping strategies rather than actively dealing with the problem. Higher use of emotion-focused coping has been found across the EDs, with the highest level in BED (Marchiol et al., 2020). Furthermore, Nagata et al. (2000) found patients with BN and the binge-purge subtype of AN used emotion-focused coping strategies more often than healthy controls, and BN patients more so than those with restrictive AN. The patients with BN also had significantly less use of task-oriented coping– trying to actively confront the problem– than the control group, leading the researchers to conclude that bulimic impulsivity is linked to higher maladaptive and lower adaptive coping strategies. Therefore, it was proposed that healthy problem-solving coping skills should be taught within treatment.

Despite using several different measures, a number of quantitative studies have concluded that using an avoidant coping style is correlated with disturbed eating attitudes and behaviours in community samples (Garcia-Grau et al., 2002; Mayhew & Edelmann, 1989) and with clinical patients (McFillin et al., 2012; Paterson et al., 2007). Lower use of seeking social or emotional support– meaning confiding in others, voicing the need for help, and looking for comfort from others– has also been associated with increased ED symptoms in clinical samples of both AN and BN (Bloks et al., 2004; Bloks et al., 2001; Yager et al., 1995). It has been proposed that challenges establishing interpersonal relationships mean people with an ED may struggle to share their problems or confide in others (Nagata et al., 2000), explaining a lack of seeking support.

As with family dysfunction, it is difficult to establish cause and effect. Bloks et al. (2001) determined that, even though inpatients showed favourable changes in their use of different coping strategies on discharge from treatment, they still had a greater usage of maladaptive coping strategies than a healthy control group. This might explain why not everyone who experiences a severe trauma or an accumulation of stressors goes on to develop an ED, implying that failure to use an effective coping strategy may exacerbate the impact.

In regard to qualitative research from the patients' perspective, one study with participants who were in treatment for AN found using their ED to help them cope was perceived to be a causal factor (Fox & Diab, 2015). In another study that asked women with BN why they thought their harmful cycle of binge eating and purging was maintained, participants reported that using their ED as a coping strategy was the reason it continued over time (Rossotto et al., 1996). Using their BN to try and maintain a sense of wellbeing or defend against negative emotions supports models related to BN serving as an affect regulation function, with the period of binge eating providing an initial escape and the act of purging then removing the anxiety about weight gain that follows the binge eating, once the initial distraction has subsided (Stice, 2002).

3.2.3.2 Emotion Regulation

Having lower levels of emotional control, and therefore finding it difficult to manage and cope with emotions, has been found to be linked to a greater drive for thinness and bulimic behaviours, further demonstrating the importance of psychosocial processes (Rozenblat et al., 2017). Emotion regulation refers to the ability to respond to emotion-inducing stimuli, including when and how the emotions are expressed (Gross, 1998), and has been found to feature in all diagnostic groups (Mallorgui-Bagué et al., 2018). Comparing AN-R, AN-BP, BN, BED and healthy controls, Brockmeyer et al. (2014) found that all of the diagnostic groups reported greater difficulties in emotion regulation than the control groups. When comparing across diagnostic subtypes, participants with BED were found to have reported fewer difficulties. Harrison et al. (2010) also found women with an ED have high levels of emotion regulation difficulties. They found women with AN to have difficulty correctly recognising emotions in others, which may suggest alexithymia or other cognitive challenges, however this was not the case for women with BN. Alexithymia, the inability to understand different emotions, has been found to be elevated across the EDs, but highest in AN (Marchiol et al., 2020).

Some other studies however have found that emotion dysregulation in individuals with BED has been correlated with emotional overeating (Gianini et al., 2013). The theory that women who develop an ED have difficulty being able to regulate their emotions effectively, and therefore use food to try and compensate is substantiated by a number of qualitative studies. Participants with AN described having difficulties being able to manage and express emotions (Fox & Diab, 2015) and participants with BN perceived their ED to be a response to experiencing negative emotions (Rossotto et al., 1996).

3.2.3.3 Low Self-Esteem

There may not be a straightforward etiological relationship between trauma and stress, in combination with ineffective coping or difficulties with emotion regulation, in influencing the onset of an ED. Fryer et al. (1997) proposed that negative stressors and poor coping strategies lead to low self-esteem, but as independent effects, and this in turn increases disturbed eating attitudes. Self-esteem refers to a person's own evaluation of their self-worth, meaning someone with low self-esteem has a critical and negative view of themselves.

There is a wealth of quantitative evidence that self-esteem is negatively correlated with harmful eating behaviours and attitudes in community samples (Brechan & Kvalem, 2015; Goldschmidt et al., 2016; Mayhew & Edelmann, 1989; Shatford & Evans, 1986; Vohs et al., 1999; Vohs et al., 2001). In clinical samples, acute and recovered patients with BN had significantly lower self-esteem than a healthy control group (Daley et al., 2008). The same has been found for acute and recovered patients with AN, but within the acute patient group BMI was negatively correlated with self-esteem (Brockmeyer et al., 2013). This finding substantiates the notion that low self-esteem is not a side effect of an ED and people with AN can attach their self-esteem to body weight, alluding to the diagnostic criteria of an over-evaluation of body weight and shape. Patients with BED have also been found to have low self-esteem, which was proposed to influence an over-evaluation of weight and shape and, in turn, self-criticism (Dunkley & Grilo, 2007).

Fryer, Waller and Kroese (1997) found self-esteem to be an imperfect mediator, implying additional variables are involved. From their review, Ball and Lee (2000) suggested that the relationship between stress or trauma, coping and EDs is mediated by the individual's internalisation of social pressure to be thin. This could mean women who attach their self-esteem to their physical appearance are at a greater risk of directing their behaviour towards eating habits if their coping strategy in response to a traumatic event is inadequate. Low self-esteem has also been correlated with interpersonal distrust, a behavioural trait believed to be present in AN and BN that constitutes part of the Eating Disorder Inventory (Garner et al., 1983). This link could be due to experiencing adversity such as abuse, as lower self-esteem has also been linked to experiencing sexual abuse (Stern et al., 1995).

A large proportion of the qualitative studies from the patients' perspective found participants identified low self-esteem as a factor in the development of their ED (Dignon et al., 2006; Gulliksen et al., 2017; Lacey et al., 1986; Redenbach & Lawler, 2003; Rossotto et al., 1996; Tozzi et al., 2002). Similar phrases such as a lack of confidence (Hsu et al., 1992) and low self-worth (Granek, 2007) were used by participants, which are also related to low self-esteem. Thus, the qualitative findings mirror the quantitative findings and support the assumption that self-esteem, despite differing definitions of this concept, could influence the risk of developing an ED.

3.2.3.4 Control

Locus of control (LoC), conceptualised as being internal or external, is the belief that either one's own behaviour determines outcomes (internal) or outside influences have control over one's fate (external) (Rotter, 1966). In addition to the already mentioned link between an external LoC and experiencing abuse, an external LoC has been found to be significantly related to general ED symptoms, AN and BN (Fouts & Vaughan, 2002; Harding & Lachenmeyer, 1986; Shatford & Evans, 1986). A reduced sense of control has been linked to a higher level of eating disturbances, and a greater desire for control has been linked with amenorrhea (Surgenor et al., 2003). In addition to lower levels of perceived internal control, Tiggemann and Raven (1998) also found a higher fear of losing self-control in women with AN and BN, but interestingly not a greater desire for control, although this measure referred to control over others. There were no diagnostic differences found in perceptions of control.

The link between EDs and feeling a lack of control has been explained as using the restriction of food intake as a way of increasing the perception of being in some form of control (Slade, 1982). Control as a potential causal factor in EDs has been raised in relation to a number of other functions. These include trying to control pubertal changes to the body and a fear of loss of control over self, failure to develop a sense of autonomy or personal control, or a reaction to societal controls over gender expectations (Surgenor et al., 2002). Expanding on this theory, Surgenor et al. (2003) proposed that different clinical behaviours within AN are linked to different aspects of control, including compensatory behaviours reflecting perceived inadequacy or failure at being in control of their body. The authors therefore proposed that not only is a person's perception of their level of control important in EDs, but also the way in which they respond to challenges to their control.

Although measuring general distress rather than eating related behaviours, Frazier et al. (2011) found a higher perceived level of present control over a traumatic event was related to lower distress, and there was a negative correlation between level of perceived present control and use of avoidant coping. They emphasised the importance of perceived levels of control at the time of the trauma on how well it is responded to and coped with, as traumatic events can harm the fundamental need for control. This demonstrates the importance of acknowledging the interaction between environmental and psychological factors in the etiology of EDs, particularly AN which involves a high level of control to sustain.

The importance of feeling in control in the etiology of EDs was also reflected in qualitative research. One of the most frequent findings appeared to be the discussion by participants of a lack of or need for control as one of the perceived reasons for their ED (Button & Warren, 2001; D'Abundo & Chally, 2004; Dignon et al., 2006; Fox & Diab, 2015; Patching & Lawler, 2009; Redenbach & Lawler, 2003; Rossotto et al., 1996).

3.2.3.5 Clinical Perfectionism

Perfectionism is a multidimensional concept. Being driven to achieve high standards is often seen as a positive quality that is linked to success and it is not until these standards are excessively high and are accompanied by extreme self-criticism that it is considered pathological (Franco-Paredes et al., 2005). Shafran et al. (2010) defined clinical perfectionism as self-evaluation being dependent on personally demanding self-imposed high standards, despite negative consequences, leading to self-criticism and a fear of failure. A relationship has been established between high levels of perfectionism and EDs in clinical research (Anderluh et al., 2003; Bardone-Cone et al., 2007; Egan et al., 2011; Shafran & Mansell, 2001; Sullivan et al., 1998; Wade et al., 2016). Levels of perfectionism have been found to remain high after treatment (Agüera et al., 2012; Lilenfeld et al., 2000; Sullivan et al., 1998), implying that the presence of the ED was not a cause. Although perfectionism has been proposed as a causal factor in BN, self-esteem may have a mediating role in the influence (Lilenfeld et al., 2000). It has been suggested perfectionism is only a predictor of bulimic symptoms when in combination with low self-esteem and body dissatisfaction (Vohs et al., 1999; Vohs et al., 2001) and for women who falsely perceived themselves to be overweight (Joiner et al., 1997). In contrast, Fryer et al. (1997) failed to find any association between perfectionism and disturbed eating attitudes, however the study was conducted using a community rather than clinical sample.

As well as quantitative evidence indicating that a certain level or type of perfectionism may be a contributing factor in developing an ED, qualitative research has also found a drive for perfection was mentioned as a perceived cause of their ED by participants with AN (Granek, 2007; Gulliksen et al., 2017; Tozzi et al., 2002) and BN (Rossotto et al., 1996). Similar to a number of quantitative studies, these participants discussed perfectionism in combination with other perceived causal factors.

3.2.3.6 Body Dissatisfaction

Quantitative studies suggest BN and BED are linked to having higher body dissatisfaction than AN (Bulik et al., 1995; Fassino et al., 2004; Laporta-Herrero et al., 2018).

However, women who have experienced AN have still been found to have a higher drive for thinness than the healthy population (Sullivan et al., 1998). A high drive for thinness, in combination with anxious or depressive behaviours, was found to predict AN (Peñas-Lledó et al., 2015). Women who met criteria for BED were also found to have greater negative body evaluations than a control group of women of the same weight (Mussell et al., 1996). Furthermore, in a sample of participants with BED, emotional and sexual abuse were found to be positively correlated with body dissatisfaction; a relationship that was mediated by self-criticism (Dunkley et al., 2010). This relationship may contribute to an explanation as to why suffering abuse may increase the risk of an ED in some women, if the traumatic experience increases body dissatisfaction.

Qualitative research found some participants with AN or BN perceived having been overweight, body dissatisfaction and wanting to lose weight as causal factors in their ED (Nevonen & Broberg, 2000; Rossotto et al., 1996), but it was not a common finding across the literature from the patients' perspective. Furthermore, Rossotto et al. (1996) found that some of their participants, recovered and non-recovered from BN, explained that weight loss and the accompanying compliments they received from others as a result was a reason they maintained the behaviour (acting as positive reinforcement) rather than being a cause of the weight control behaviours. The evidence overall suggests body dissatisfaction may be a greater contributing factor in BN and BED than AN, and this potential distinction may demonstrate a difference in their etiology that could warrant a different treatment approach.

3.2.3.7 Character Dimensions

Building on their earlier work on the dimensions of temperament, Cloninger et al. (1993) went on to identify a further three aspects of personality known as character dimensions: self-directedness (ability to express oneself and direct one's life in accordance with personal beliefs), self-transcendence (feeling part of a larger world) and cooperativeness (tendency to accept and understand others). These dimensions are based on an individual's self-concept of who they are and how they fit into society, which is learned through experiences. Along with the previously described NS, HA, RD and P, these seven dimensions of personality make up the Temperament and Character Inventory (TCI). The dimensions of the TCI have been tested in different clinical conditions, including with EDs. Findings in relation to self-directedness are consistent, suggesting that low levels are associated with EDs (Bulik et al., 2000; Diaz-Marsa et al., 2000; Fassino et al., 2002; Klump et al., 2000; Klump et al., 2004). Low self-transcendence appears to be associated with restrictive AN and purge-only AN, but not BN (Klump et al., 2000; Klump et al., 2004). Self-transcendence has also been found to differentiate between AN patients who have dropped out of and completed a course of treatment (Jordan et al., 2017; Pham-Scottez et al., 2012), suggesting it may be a factor to understand for recovery. Finally, the literature on cooperativeness is mixed, with low levels found in AN (Bulik et al., 2000; Klump et al., 2000), low levels in BN but not AN (Fassino et al., 2002), and low levels in people who had been diagnosed with both AN and BN but high levels in people with either AN or BN (Klump et al., 2004). This, like RD, appears to need further study.

3.2.4 Etiology Summary

The literature review on etiology identified a wide range of factors that may cause EDs. Most etiological studies have used quantitative methods with clinical samples of ED patients or, due to difficulties accessing clinical patients, measured ED symptomatology in a general population sample (Polivy & Herman, 2002). Some research focused on the extent to which one specific causal factor influenced the onset of an ED, but numerous studies provided evidence that multiple factors are often present and interact with each other, demonstrating that a psychosocial approach to the etiology of EDs provides a more robust account than looking at each factor in isolation.

In comparison to quantitative research, only a small number of studies have taken a qualitative approach that allowed people to describe their own experiences and opinions on what caused their ED, without confining questions to predefined foci. Those studies consisted of: nine on AN (Beresin et al., 1989; Button & Warren, 2001; Dignon et al., 2006; Fox & Diab, 2015; Granek, 2007; Gulliksen et al., 2017; Hsu et al., 1992; Nilsson et al., 2007; Tozzi et al., 2002), two on BN (Lacey et al., 1986; Rossotto et al., 1996), three that did not distinguish between ED diagnoses (D'Abundo & Chally, 2004; Patching & Lawler, 2009; Redenbach & Lawler, 2003), and one comparing AN and BN (Nevonen & Broberg, 2000). The latter study failed to find any meaningful diagnostic differences, possibly due to identifying overarching themes rather than conducting a more in-depth analysis.

Quantitative and qualitative findings were consistent in a number of areas. Firstly, difficulties in relationships with parents and/or peers, ineffective coping strategies, difficulties in emotion regulation, low self-esteem, feeling a lack of control and perfectionism were consistently identified as potential causal factors across all ED diagnoses. Body dissatisfaction was higher in people with EDs than the general population, but high body dissatisfaction appeared to be a greater influence in BN and BED than AN. Diagnostic differences have also been found in quantitative data for trauma and stressful life events, with evidence suggesting an increased prevalence of these experiences in all EDs but with the highest rates in people with BN. The difference between AN and BN in relation to experiences of sexual abuse was more evident in the quantitative studies but less clear in the qualitative data. This difference could be due to the varying definitions of trauma between the researcher and the participant.

Despite the similarities, there were also some important differences between the quantitative and qualitative findings. Firstly, participants in qualitative studies spoke of the impact of witnessing parental marital conflict, whereas quantitative research into the role of parents in the development of EDs focused on the direct relationship between the child and parent(s). Secondly, additional factors of doubts over femininity (Tozzi et al., 2002) and a lack of a sense of belonging (Patching & Lawler, 2009) were considered important in the qualitative studies but overlooked by the quantitative research. Biological predispositions, on the other hand, were not mentioned by participants in the qualitative research reviewed here. It also appears that findings of significant associations between specific variables and ED diagnoses have been used as evidence to infer certain factors are causes of EDs rather than considering that they may in fact be maintenance factors. For example, media influence was discussed by participants in qualitative studies as a reason why their ED was maintained over time rather than as a causal factor. Maintenance factors are discussed in more detail in the next section below.

Although these qualitative methods rely on the retrospective account of the participants, and participants may not fully understand the factors behind the development of their disorder, the studies provide a valuable insight that researchers cannot gain from quantitative study alone. Qualitative methodology is under-represented in the literature, especially for women with BED, and in depth comparisons between ED diagnoses are scarce. Both quantitative and qualitative approaches provide useful data, and do not need to be carried out in isolation. At the time of writing, however, no study has used both methods alongside each other with the same sample to examine whether inferences drawn by researchers from quantitative data analysis are supported by the participants themselves. Instead, studies from the perspective of those with lived experience have been conducted in isolation.

3.3 Maintenance Factors

In addition to causal factors, this thesis also sought to explored perceived maintenance factors. As outlined in Chapter 2, one of the diagnostic criteria for both AN and BN is using weight and shape as a means of self-evaluation (Stice et al., 2013). It has been theorised that basing self-worth on weight, shape and/or eating behaviours, and the perceived ability to control them, is central to the maintenance of EDs. Investigating the course of BN over a 5 year period, greater levels of self-evaluation based on weight and shape predicted persistence of binge eating (Fairburn et al., 2003b). Targeting over-evaluation of weight and shape alone was reaching recovery rates of less 50% however, so it was determined that this was not a complete explanation (Fairburn et al., 2003a).

High levels of perfectionism have been proposed to impede treatment of psychological disorders (Shafran & Mansell, 2001). Over a 10 year follow up period, perfectionism was found to be a significant predictor of ED maintenance for both AN and BN (Holland et al., 2013). Stice (2002) conducted a meta-analytic review of maintenance factors in EDs and determined that perfectionism was a maintenance factor for general eating pathology, whereas perceived pressure to be thin had a small but nonsignificant influence. Poor social adjustment, suggesting a difficulty in establishing and maintaining relationships, has been found to predict persistence of binge eating in people with BN (Fairburn et al., 2003b). Negative affect has been reported to be a maintenance factor for binge eating, and thin ideal internalisation and body dissatisfaction were considered to maintain BN pathology (Stice, 2002). In a sample of women who met the criteria for BED, being primed with a negative mood induction triggered binge eating, and levels of anxiety decreased following the binge eating episode (Agras & Telch, 1998). The authors concluded that, when faced with negative emotions, binge eating reduced the anxiety associated with a lack of adaptive regulation skills. These findings provide additional evidence that BED may be maintained due to its affect regulation function. AN is also considered to serve a number of perceived positive functions, which maintains the disordered eating behaviours. Gregertsen et al. (2017) determined, from a review, that there were five main ways in which AN is valued: providing a sense of control, a way to avoid emotions, feeling a sense of mastery, increasing self-confidence, and to communicate distress.

Bringing together research evidence examining the maintenance of EDs, two well established maintenance models have been developed. Focusing on AN, the cognitive-interpersonal maintenance model of anorexia nervosa (Schmidt & Treasure, 2006) centres on a combination of psychological and social factors: perfectionism (perceiving eating to be failure), difficulties tolerating emotions (numbed by a preoccupation with food), and reactions from close others to their AN (receiving increased attention or needing to distance from others due to criticism). The model also focuses on the perceived positive role of AN and the value often placed on the illness that influences a reluctance to change. Sharing some similarities, but extending the model to also include BN and EDNOS, Fairburn et al. (2003a) developed a transdiagnostic theory of the maintenance of EDs, incorporating perfectionism, core low self-esteem, problems tolerating negative moods and interpersonal difficulties, alongside an over-evaluation of weight and shape.

The quantitative findings and models are echoed by the voices of participants in qualitative research. Reasons participants attributed to the persistence of their ED included it being a way to cope with any stress and trauma (Jenkins & Ogden, 2012), relieving or dampening negative emotions (Gulliksen et al., 2017; Lacey et al., 1986), providing an escape from overwhelming emotions (Rossotto et al., 1996), being a way to feel in control (Button & Warren, 2001; Rossotto et al., 1996) and reinforced by peer pressure (Granek, 2007). Participants with AN also described gaining confidence from their ED as it felt like an achievement (Fox & Diab, 2015; Gulliksen et al., 2017), which could imply it aligned with their perfectionism. Perfectionism was also suggested by some participants with AN to be why they were able to maintain such a high level of dietary restriction (Dignon et al., 2006). Furthermore, as previously discussed, media influence was also perceived to be a maintenance factor by people with lived experienced of an ED, particularly portrayals of a thin ideal body type (Dignon et al., 2006; Redenbach & Lawler, 2003). Emotion regulation, control, perfectionism and peer pressure are therefore factors that are considered to be involved in the maintenance of EDs, as well as the etiology. This demonstrates the overlap that can occur between causal and maintenance factors.

3.4 Treatment Efficacy/Effectiveness and Factors Influencing Outcomes

As detailed back in Chapter 2, there are a range of different psychological treatments for EDs. As the current thesis included a focus on experiences and perceptions of treatment, existing literature on treatment efficacy provides important context. Despite work to improve treatment efficacy, some treatment outcomes are still considered unsatisfactory (Abbate-Daga et al., 2016) and the best course of treatment remains uncertain (Treasure et al., 2020). In an attempt to improve the adherence to and effectiveness of treatment, a range of research has been conducted. As explained in section 2.5.4, in line with the psychosocial framework of this thesis, the focus here is on psychological therapies, with pharmacological treatment out of the scope of this thesis.

3.4.1 General Treatment Outcomes

Determining outcome rates is difficult due to the range of definitions of recovery used, as discussed in Chapter 2. A large scale review of 119 studies, totaling 5,590 patients who had received treatment for AN, estimated less than half of those who were still surviving at follow-up could be considered to be recovered. The study concluded that the outcome rate for

AN did not improve over the course of the 20th century, although the author emphasised the variations in outcomes measures used across the studies (Steinhausen, 2002). A more recent large scale 30-year outcome study of AN found less than two-thirds of participants had been free of symptoms for at least six months at follow-up (Dobrescu et al., 2020).

Similar results have been found for BN, with an estimation from a review of 79 studies that 42 - 60% of patients were considered recovered at follow up after treatment, depending on the definition of recovery (Steinhausen & Weber, 2009). Furthermore, a more recent review failed to find any improvement, with only just over a third of participants fully abstaining from symptoms of BN post-treatment (Linardon & Wade, 2018).

For binge eating disorder, methods of treatment and subsequent outcomes are widely varied making establishing an overall outcome rate difficult (Murray, 2020). Linardon (2018) however conducted a meta-analysis and found less than half of participants abstained from binge eating after treatment.

One issue with treatment outcome is likely to be the high rate of people who drop out of treatment prematurely. A review estimated between 20 – 40% of outpatients with AN drop out from treatment, depending on the type of treatment (DeJong et al., 2012). In addition, a review of relapse in AN found rates of up to 52% (Khalsa et al., 2017). For BN, a review concluded that although recovery rates varied from 38 – 73%, around a third of those who were considered as recovered went on to relapse (Berkman et al., 2007). The same review determined there were insufficient long-term studies into relapse rates in BED to draw a reliable conclusion.

3.4.2 Efficacy of Specific Treatment Modalities

The common focus across the majority of treatments for EDs is on restoring normal patterns of eating, and weight restoration where relevant, but there are differences in the focus and delivery of additional treatment aspects. Dietary or nutritional counselling alone is considered to be less effective (Serfaty et al., 1999). Randomised control trials (RCTs) are the principal method of examining the effectiveness of different types of treatment for EDs and research shows that some forms of therapy can be more efficacious for some clients (Waller, 2016b). There are a wide range of treatments available, and variants of certain therapies, and therefore the most widely used and researched treatment modalities will be reviewed here.

3.4.2.1 Cognitive Behavioural Therapy (CBT)

CBT is the most widely researched treatment for EDs, especially for BN and BED, and evidence suggests CBT may be the most effective treatment across the EDs in adults (Waller, 2016a). For both BN and BED, a meta-analysis of RCTs into the efficacy of CBT found greater improvements in behavioural and cognitive symptoms with both therapist-led and self-led CBT than alternative forms of psychotherapy (Linardon et al., 2017). CBT appeared to only be superior to active alternatives, however, when an enhanced form (CBT-E) focusing on certain maintenance mechanisms was delivered (which will be expanded upon in section 3.4.3). For AN, recovery rates using CBT-E have been estimated at around 30%, which, despite remaining low, is reported to be higher than other psychological treatments (Waller, 2016a).

3.4.2.2 Family Based Treatment (FBT)

FBT has been well established as the most effective form of treatment for children and adolescents with AN, and possibly BN, with a review estimating remission rates of around 40% (Lock & le Grange, 2019). Meta-analyses suggest FBT may be more effective than individual treatment as usual (Fisher et al., 2019), particularly after long-term follow-up (Couturier et al., 2013), but the authors recommend further research is required for different age groups. An RCT comparing FBT with individual therapy for adolescents with AN found remission rates were superior at 6 and 12-month follow-ups for FBT (Lock et al., 2010). For BN, results were less definitive; FBT was found to be more significantly more effective than supportive psychotherapy at the end of treatment but the difference was less substantial at a 6-month follow up (le Grange et al., 2007).

3.4.2.3 Interpersonal Psychotherapy (IPT)

IPT has received mixed outcomes dependant on ED diagnosis. For AN, a review reported that there were no significant differences in the outcomes rates between IPT and CBT (Miniati et al., 2018). The same review determined that, for BN, CBT and CBT-E were superior to IPT. There is less evidence investigating the role IPT in BED, but an RCT into psychological treatments for BED found 81.8% who had CBT compared with 64.4% of who had IPT were considered recovered at the end of treatment (Hilbert et al., 2012). At long term follow up (>1 year) however, CBT had dropped to 52% and IPT had increased to 76.7%. This delay in response could suggest IPT may have some long-term benefits for BED.

3.4.2.4 Maudsley Anorexia Nervosa Treatment for Adults (MANTRA)

Evaluation of a course of MANTRA with adults with AN (details of what the treatment entails is expanded upon in the next section 3.4.3) found an 82% completion rate and 48% of those participants were deemed as having a good or moderate outcome at a 12-month follow up, measured through BMI and eating pathology scores (Wade et al., 2011). Reviewing treatment options for severe and enduring AN, Hay et al. (2012) suggests MANTRA may show some promise that warrants further investigation.

3.4.2.5 Specialist Supportive Clinical Management (SSCM)

SSCM was developed as an active control therapy for a trial comparing CBT and IPT for AN, in which the focus is on symptoms, eating behaviours and building a therapeutic relationship. Contrary to expectations, outcomes at post-treatment were superior for SSCM, with 56% of participants rated as having a good or moderate outcome (McIntosh et al., 2005). At a >5 year follow up, however, the outcomes for the three different therapies were indistinguishable, with an average of 28%.(Carter et al., 2011). Further trials have determined SSCM to be comparable to MANTRA (Schmidt et al., 2015) and CBT-E (Byrne et al., 2017).

In summary, quantitative evidence suggests that FBT can be beneficial for adolescents. For adults, no single approach to treatment has demonstrated superiority (Watson & Bulik, 2013) but CBT and IPT have shown some positive outcomes for all EDs. The views of the clients, however, are missing. While accepting that patients can disagree with therapists, particularly if they are ambivalent to change, feedback from consumers can provide an important contribution to the evaluation of treatment. Qualitative research has reported negative views of AN and BN patients about the helpfulness of general hospital admission care, general practitioners (De Le Rie et al., 2006), force feeding (Deloitte Access Economics, 2012) and eating-focussed behavioural therapy and strategies (le Grange & Gelman, 1998; Newton et al., 1993). FBT has received mixed views, with some reporting it as helpful, others that it is good in certain situations, and some that it has been unhelpful or even made the situation worse (Beresin et al., 1989; Hsu et al., 1992; le Grange & Gelman, 1998; Newton et al., 1993; Rosenvinge & Klusmeier, 2000; Tierney, 2008).

Encouragingly though, qualitative research shows a range of treatments have received some positive feedback and are considered helpful in some way, including specialist psychologists, psychiatrists (Deloitte Access Economics, 2012), specialist ED centres (De Le Rie et al., 2006), counselling (Button & Warren, 2001; Happell, 2008; Newton et al., 1993;

Tozzi et al., 2002), psychoeducation, CBT, coping behavioural strategies (le Grange & Gelman, 1998), individual psychotherapy (Button & Warren, 2001; Hsu et al., 1992; Rosenvinge & Klusmeier, 2000; Tierney, 2008; Tozzi et al., 2002), group therapy (Beresin et al., 1989; Deloitte Access Economics, 2012; Newton et al., 1993) and self-help groups (De Le Rie et al., 2006; Newton et al., 1993; Pettersen & Rosenvinge, 2002; Rosenvinge & Klusmeier, 2000; Tierney, 2008). Nonetheless, there are certain caveats surrounding some of the positive views regarding the specific delivery of the treatments, which will be discussed is section 3.4.4.

3.4.3 Factors Predicting Treatment Outcomes – Quantitative Research

In addition to measuring ED symptoms before and after different types of treatment to determine which treatments are most efficacious, research has also been conducted to investigate whether there may be other factors that influence treatment outcomes; that is factors that moderate or mediate treatment outcome. A higher level of self-esteem (Fairburn et al., 1993; Halmi et al., 2005; Vall & Wade, 2015), better interpersonal functioning (Vall & Wade, 2015), a strong therapeutic alliance (Graves et al., 2017) and internal motivation (Steiger et al., 2017) have been found to predict a more positive treatment outcome across the EDs. Predictors of a better treatment outcome also included an internal LoC in AN (Strober, 1982), higher self-directedness in BN (Bloks et al., 2001), using reassuring thoughts as a coping strategy in both AN and BN (Bloks et al., 2001), and lower body dissatisfaction in BED (Lammers et al., 2015). In those with AN, low levels of self-esteem and ineffectiveness (Wade et al., 2011), and high levels of perfectionism and mood intolerance (Vall & Wade, 2017) predicted a poorer treatment outcome. Difficulties identifying feelings was also found to predict a poorer outcome in treatment for both AN and BN (Speranza et al., 2007). A meta-analysis also reported that familial problems in studies for AN and BN predicted a worse outcome (Vall & Wade, 2015). The authors in that review noted however that there were insufficient data to robustly compare predictive factors for treatment outcomes across ED diagnoses. A number of factors that predicted a poorer treatment outcome (self-esteem, perfectionism and difficulties understanding and tolerating with emotions) align with the previously discussed maintenance factors in EDs.

Stice (2002) proposed that, while understanding the risk factors for EDs can have implications for prevention, understanding the maintenance factors that predict symptom persistence has important implications for treatment. Identifying a way in which maintenance factors can be targeted during treatment may help to improve outcome rates (Agras et al., 2004). Regarding the role of control in EDs, Vandereycken and Vansteenkiste (2009) examined the impact of involving inpatients in decisions about their treatment. They found that giving their patients a choice on entering a treatment programme had positive effects, but only for the first month. The basic principles of the treatment programme were then the same for both groups, suggesting that this research needs to be expanded upon to look at the influence of having more active involvement in decision-making throughout treatment. Trials seeking to reduce perfectionism by introducing a perfectionism-specific module into CBT treatment of EDs have failed to enhance treatment outcomes in comparison to standard CBT (Goldstein et al., 2014; Steele & Wade, 2008).

Based on the transdiagnostic theory of the maintenance of EDs, an adapted form of CBT was developed (CBT-Eb) targeting the maintenance factors (perfectionism, low self-esteem, problems tolerating negative moods and interpersonal difficulties) as well as ED psychopathology. Compared with CBT-Ef (focusing on ED psychopathology alone) in a RCT, patients with the specific problems addressed by the CBT-Eb had a better outcome when receiving this broad treatment over the focused alternative, however the reverse occurred in patients without these factors present (Fairburn et al., 2009). These findings emphasise the importance of a comprehensive prior assessment to tailor individualised treatment plans based on the presence of maintenance factors to maximise effectiveness.

MANTRA uses strategies aimed to address perfectionism, difficulties tolerating emotions and reactions from close others (maintenance factors set out in the cognitive-interpersonal maintenance model of AN), alongside motivational interviewing techniques to encourage self-motivation (Schmidt et al., 2014). Tested alongside SSCM, however, both methods yielded improvements in BMI and ED symptomatology (Schmidt et al., 2015) and there were no significant differences found between the outcomes of the two treatments. Feedback from the patients themselves did however reveal a difference, with patients who received MANTRA giving positive feedback to a greater extent than those who received SSCM. This difference provides support for the importance of considering the views of treatment consumers and the client's perspective.

3.4.4 The Client's Perspective on Treatment – Qualitative Research

Considering the client's view on the treatment they received could provide new insights that researchers may have overlooked. This may particularly be achieved using a qualitative approach in which participants can talk in depth about the whole treatment experience, rather than focusing on outcomes. For example, self-help groups, group therapy and peer support have been found to often be considered helpful as they allow the sharing of experiences, feelings, support and advice with those who have been or are going through a similar ordeal. Participants with AN however have reported negative aspects including competition and learning harmful habits (Beresin et al., 1989; Colton & Pistrang, 2004; De Le Rie et al., 2006; Granek, 2007; Offord et al., 2006; Tierney, 2008). In comparison to the caution expressed by women with AN, women with BED rated group therapy as the most helpful treatment, over individual therapy and a dietician or nutritionist (Higgins Neyland & Bardone-Cone, 2019).

Although psychotherapy has generally been positively received, the qualities of the individual therapist and their relationship with the client was one of the most frequently discussed elements in relation to treatment and recovery in the qualitative literature. Therapists were preferred by clients if they were knowledgeable, empathetic, understanding (De Le Rie et al., 2006; Escobar-Koch et al., 2010; Fox & Diab, 2015; Pettersen & Rosenvinge, 2002; Rorty et al., 1993; Tierney, 2008), non-judgemental (Beresin et al., 1989; Escobar-Koch et al., 2010), respectful (De Le Rie et al., 2008; Gulliksen et al., 2012), honest, trustworthy, and showed genuine care (Rance et al., 2017b). Having a good rapport with practitioners appears to be important, as patients described the importance of establishing and maintaining a good therapeutic alliance (Button & Warren, 2001; Swain-Campbell et al., 2001) and how difficult it was to be able to maintain outside relationships whilst in inpatient treatment, often leaving them feeling abandoned and isolated (Fox & Diab, 2015). Other positive factors mentioned include ensuring patients feel supported and validated (Federici & Kaplan, 2008), discussing feelings, building self-confidence (Beresin et al., 1989; De Le Rie et al., 2008), being firm but not controlling (Beresin et al., 1989), setting appropriate and meaningful goals (Fox & Diab, 2015), encouraging normal activities and connections to the outside world (Offord et al., 2006), and allowing patients to have some autonomy, control, and make collaborative decisions (Colton & Pistrang, 2004; Escobar-Koch et al., 2010; Offord et al., 2006). Reviewing this list of factors perceived as helpful in treatment, they appear to reflect the benefits of addressing low self-esteem, feeling a lack of control and not having a social support network.

Furthermore, the most common responses from patients across all ED treatment were the importance of addressing the psychological and emotional issues as well as the physical symptoms, by understanding the underlying cause(s) (Beresin et al., 1989; Colton & Pistrang, 2004; De Le Rie et al., 2006, 2008; Escobar-Koch et al., 2010; Federici & Kaplan, 2008; le Grange & Gelman, 1998; Offord et al., 2006; Pettersen & Rosenvinge, 2002; Rorty et al., 1993; Tierney, 2008), treating the patients rather than the illness (Colton & Pistrang, 2004; De Le Rie et al., 2008; Pettersen & Rosenvinge, 2002; Rance et al., 2017b; Tierney, 2008), and receiving personalised treatment programmes to address their individual needs (Escobar-Koch et al., 2010; Offord et al., 2006; Swain-Campbell et al., 2001). These findings recognise that different causal and maintenance factors may be present in different individuals and therefore individualised treatment is required for it to be most effective. However, when both patients and therapists were given a list of criteria and asked to select the top ten they considered to be most important to recovery, the staff failed to place addressing the underlying issues in their top ten, but the patients felt it should be a priority (De Le Rie et al., 2008). De Le Rie et al. (2008) also found that therapists selected a focus on weight, improving body image, learning to eat normally and keeping an eating diary; the patients, on the other hand, selected treatment that addresses the person and focus on self-esteem, as well as addressing underlying problems. This difference shows a clear gap between the views of the staff and the patients, and therefore the importance of incorporating the views of service users, in addition to considering the knowledge of professionals and evidence from clinical trials.

Not only may consumer perceptions contribute towards expanding current knowledge of EDs, but understanding and addressing the beliefs of people with lived experience may be an important aspect of improving outcomes. Although considering mental health in general, Petrie et al. (2008) suggest that a patient’s view of the causes of their illness will influence what types of treatments they believe will be effective and, therefore, their response to different treatment plans. This has been found to be the case with general psychotherapy (Constantino et al., 2018) and bipolar disorder (Pollack & Aponte, 2001), however there is very limited research in the area, especially focusing on EDs. Jordan et al. (2017) found low levels of perceived treatment credibility predicted premature dropout from treatment for AN, demonstrating the importance in understanding the clients' views of their treatment.

Although this thesis focuses upon the factors within treatment that can impact upon recovery, it is important to also note that there are additional factors outside treatment that can influence recovery. Participants with a lifetime history of an ED have identified a number of factors external to treatment that they perceived to have contributed towards recovery: positive life events or changes such as having children, starting a new school or job, moving house or a new romantic relationship (Beresin et al., 1989; Granek, 2007; Hsu et al., 1992; Nilsson & Hagglof, 2006; Pettersen & Rosenvinge, 2002; Rorty et al., 1993), their own willpower and determination to recover (Button & Warren, 2001; Federici & Kaplan, 2008; Halvorsen & Heyerdahl, 2007; Nilsson & Hagglof, 2006), a realisation of their own mortality (Nilsson & Hagglof, 2006; Rorty et al., 1993), and friends, family and partner support (Federici & Kaplan, 2008; Granek, 2007; Hsu et al., 1992; Nilsson & Hagglof, 2006; Pettersen & Rosenvinge, 2002; Rorty et al., 1993; Tierney, 2008). Greater understanding of influences outside of treatment and incorporating aspects within treatment, such as enhancing family relationships, facilitating fresh starts, or on-going support once patients have been discharged, may minimise chances of relapse.

3.4.5 Treatment Summary

There are a range of different psychological treatments for EDs, some of which appear more effective depending on the diagnosis or age of the client (e.g. FBT has proven more effective for children and adolescents with AN). Despite the variety of treatments, only around half of people across all EDs are achieving good outcomes, demonstrating a clear need for improvement in treatment efficacy. Quantitative studies have suggested a number of psychological and social factors to be linked with a more positive treatment outcome, such as higher self-esteem, better interpersonal functioning and use of reassuring thoughts (considered a healthy coping strategy). Lower levels of self-esteem, higher levels of perfectionism and difficulties coping with emotions have been linked to poorer treatment outcomes. It has been proposed that these factors may contribute to the maintenance of EDs, and targeting maintenance factors in treatment may be beneficial. In addition, qualitative research has emphasised the importance clients place on the therapeutic relationship and being treated as an individual. Diagnostic differences have also been implied through the qualitative findings, with participants with AN having reservations about using group support and therapy due to peer pressure and negative competition in a shared environment.

Supporting a psychosocial approach, both quantitative and qualitative methods have reported positive findings for treatment types that address multiple factors, both causal and maintenance. Research into which specific aspects of these treatment programmes or their delivery are helpful, or perceived as such by the consumer, is limited. Only a small number of studies have established recommendations based on incorporating knowledge of causal and maintenance factors in an attempt to improve treatment efficacy, for example giving patients a sense of autonomy, despite the obvious potential. The fact that individuals respond differently to the same treatment suggests that psychological traits may influence the type of treatment they need and their response to treatment, or that different causal and maintenance factors are operating. Furthermore, the emphasis that those with an ED place on the relationship between client and therapist is noteworthy, illustrating the importance of social connection both within treatment and after discharge. Better social engagement and support may assist in reducing relapse rates.

Despite the fact that qualitative studies have begun to focus on the views of people with a history of an ED, those studies have tended to focus on treatment and/or recovery separately to causes and/or maintenance factors. Only eight studies have actually asked participants about their perception of both causes and/or maintenance factors, and treatment, two of which just reported on EDs as a group and focused on specific themes (D’Abundo & Chally, 2004; Patching & Lawler, 2009). Consequently, there are only six studies inductively exploring the experience of AN, including both causes and treatment, from the perspective of participants with lived experience. Four of these studies still failed to draw any links between causes or maintenance factors and treatment (Beresin et al., 1989; Button & Warren, 2001; Hsu et al., 1992; Tozzi et al., 2002), and one asked participants about recovery rather than treatment so drew their own conclusions about what patients might prefer in treatment (Granek, 2007). One study used a sample of current inpatients, which could skew the findings as they may not be able to view treatment objectively whilst still in the middle of a programme, and were unlikely to have experience with recovery (Fox & Diab, 2015). Only one study focused on BN and it was split into two papers; one focusing on causes and maintenance factors (Rossotto et al., 1996) and one focusing treatment and recovery (Rorty et al., 1993). Research from the perspective of women with BED is extremely limited, with no studies identified that investigated causes and only one which looked at treatment preferences (Higgins Neyland & Bardone-Cone, 2019). It was therefore established from this literature review that qualitative research considering the causes, maintenance, treatment and recovery of AN, BN and BED, and the links between these stages, is missing.

3.5 Conclusion

Current research suggests that there are a multitude of psychosocial factors acting in combination to cause an ED, including relationship struggles with parents or peers, ineffective coping strategies, emotion regulation difficulties, low self-esteem, feeling a lack of control and perfectionism. Body dissatisfaction and experiencing trauma also appear to be involved in the onset of an ED, particularly for BN. Placing an over-emphasis on weight and shape as a means of self-evaluation, low self-esteem, perfectionism, using the ED as a means of coping with negative emotions and to gain a sense of control, peer pressure, and media portrayals of the thin-ideal body type appear to be involved in the maintenance of EDs. Ongoing body dissatisfaction has been suggested to be a maintenance factor that is especially present in BN. Several factors therefore appear to be involved in both the etiology and maintenance of EDs, demonstrating the difficulty that can sometimes arise when looking to make a clear distinction between causal factors and maintenance factors.

Despite the similarities, there are also differences in the social experiences and psychological characteristics not only between diagnostic groups but individuals. Therefore, it is not surprising that clients stated they felt treatment would be more effective if individual plans were delivered based on their personal circumstances. Yet, there is limited research investigating the efficacy of individual treatment plans or seeking to establish which treatment is most appropriate for which combination of causal factors, resulting in a lack of evidence to be able to match clients to treatment (Treasure & Schmidt, 1999). Research targeting maintenance factors (e.g. CBT-Eb) has begun to yield some promising results, but detailed research into the clients' experiences with treatments and how they think treatment could be improved is limited, and room for improvement remains. Furthermore, at the time of writing, no qualitative research was found that considered causes, maintenance factors, treatment and recovery holistically. There is therefore a gap in the current research establishing links between a participant's views on what caused their ED, why their ED was maintained, their experience with treatment, and views on what was helpful within treatment for recovery. Additionally, qualitative research with women with BED, and studies drawing meaningful comparisons among the experiences of women in different diagnostic groups, is extremely scare.

3.6 Thesis Aims and Objectives

As previously outlined, this PhD consists of two studies: a quantitative study and a qualitative study. Each study had its own aim and objectives that are set out in the relevant chapter, but shared the core aim of this thesis. To reiterate, the overall aim was to use mixed methods to establish a better understanding of the key factors that influence the onset and maintenance of an eating disorder and the factors that are linked to effective treatment and recovery, from the perspective of a New Zealand sample of women with lived experience of an eating disorder. There were four key objectives:

1. To identify the psychosocial factors a sample of women with lived experience of an eating disorder perceived contributed to the onset, maintenance and recovery of their disorder, including factors within treatment.
2. To explore how recovered and non-recovered participants compared in their views and experiences of their eating disorder, including factors that contributed to the onset, maintenance and effectiveness of treatment.
3. To explore whether there were diagnostic variations in the participants’ experiences and views of factors that influenced onset, maintenance, treatment and recovery.
4. To compare the findings from the quantitative study with those from the qualitative study to provide an integrated understanding of the key psychosocial factors perceived to be related to the onset, maintenance, treatment and recovery of EDs.

CHAPTER FOUR: A Quantitative Study Exploring Causal and Recovery Factors in Eating Disorders, from the Perspective of Women with Lived Experience

4.1 Introduction

In this quantitative study, the views of women with lived experience of an ED were assessed in regard to both causal and recovery factors. This chapter begins by recapping the key causal and recovery factors in EDs established in quantitative literature reviewed in Chapter 3. Next, the objectives and associated hypotheses, based on the review, and the methods employed are described. Detailed results, addressing each of the study objectives, are presented. The findings are then discussed in relation to the hypotheses, existing literature and PhD theoretical framework. Finally, the strengths, limitations and implications of the study are presented.

4.1.1 Key Findings from the Quantitative Literature

As noted in the literature review in Chapter 3, the etiology of EDs is complex, with evidence for biological, social and psychological factors. Consistent with the psychosocial framework for this thesis, previous research suggests a variety of psychological and social components contribute to the onset of an ED. In terms of EDs in general, the key etiological social factors identified in the review included: being teased by peers about appearance (and subsequent body dissatisfaction) (Sweetingham & Waller, 2008), thin-ideal media exposure (Grabe et al., 2008), and low perceived parental care or overprotectiveness (Calam et al., 1990). Psychological factors for which there is considerable evidence included: low self-esteem (Brechan & Kvalem, 2015), an external locus of control (Fouts & Vaughan, 2002), high perfectionism (Bardone-Cone et al., 2007), emotion regulation difficulties (Brockmeyer et al., 2014) and ineffective coping strategies, particularly avoidant coping (Garcia-Grau et al., 2002) rather than seeking social and emotional support (Bloks et al., 2001). The temperament and character dimensions of high harm avoidance (Fassino et al., 2002) and low self-directedness (Klump et al., 2000) have also been found to be linked to an ED.

Although there are a number of factors common to the etiology of all EDs, there have also been some diagnosis specific findings. The temperament and character dimensions of low novelty seeking, high persistence (Fassino et al., 2002) and low self-transcendence (Klump et al., 2000) have been reported as causal factors for AN. In contrast, the onset of BN has been linked to high novelty seeking (Fassino et al., 2002), childhood sexual abuse (Waller, 1991) and stressful life events (Ball & Lee, 2000). BN and BED have been attributed to high levels of body dissatisfaction to a greater extent than AN (Bulik et al., 1995; Fassino et al., 2004).

In relation to the treatment of EDs, RCTs have demonstrated psychological therapies such as CBT to be more efficacious than pharmacological and symptom-specific behavioural treatments (Serfaty et al., 1999; Waller, 2016a). FBT has been established as the most effective treatment for adolescents with AN and possibly also BN (Lock & le Grange, 2019). For adults, a preferred treatment for AN has not been established (Watson & Bulik, 2013), but for BN and BED it appears that CBT and IPT have positive outcomes in comparison to alternative options (Hilbert et al., 2012; Linardon et al., 2017). Some treatment guidelines recommend group therapy for BED (National Institute for Health and Care Excellence [NICE], 2017).

Within treatment, some individual factors have been found to influence outcome. Factors commonly associated with a positive treatment outcome include the patient using reassuring thoughts as a coping mechanism (considered a healthy coping strategy) (Bloks et al., 2001), having high self-esteem (Halmi et al., 2005; Vall & Wade, 2015) and having good interpersonal functioning (Vall & Wade, 2015). A strong therapeutic alliance has also been linked to a more positive treatment outcome (Graves et al., 2017). Factors including high perfectionism and mood intolerance have been found to predict a poorer treatment outcome (Vall & Wade, 2017). Focusing on psychosocial factors that have been linked to a poor or positive outcome in treatment has the potential to improve treatment efficacy. Research has begun to investigate the influence that incorporating factor-specific modules into therapy may have on treatment outcomes, for example a perfectionism-specific module within a course of CBT (Goldstein et al., 2014). Despite the ongoing research, treatment outcomes still have considerable room for improvement.

One area in which the literature is limited is in seeking the views of people with lived experience of an ED. No research was identified that collected these views in a quantitative format that enabled statistical comparison between AN, BN and BED, or recovered and non-recovered participants, yet determining differences could have important clinical implications, including tailoring treatment depending on diagnosis to improve efficacy. Furthermore, there are few studies that have collected perceptions of both causal and recovery factors within the same sample, making it difficult to ascertain whether a patient's views on the causes of their disorder may influence what they find helpful for recovery. These are important gaps which the present study sought to fill.

As established in Chapter 3, there can be a blurred line between etiology and maintenance, with factors such as perfectionism and self-esteem considered in both categories. Maintenance factors were not included within the present study as the literature states a clear differentiation should be made between risk and maintenance factors (Stice, 2002) but there are inconsistent definitions (Jacobi et al., 2004). It is recommended for survey design within the healthcare setting that the use of unfamiliar terms or medical jargon is avoided as there is a risk of response error through misunderstanding (Sinkowitz-Cochran, 2013). It was therefore anticipated that it may be difficult to provide participants with a clear enough definition of a maintenance factor using the survey method employed in the present study. Maintenance factors were however able to be explored in the next chapter through the qualitative methods.

4.1.2 Objectives, Hypotheses and Research Questions

The aim of this quantitative study was to improve understanding of the factors a New Zealand sample of women with lived experience of an ED perceived to be important in causing their ED and that contributed towards their improvement or recovery (including factors within and outside of treatment). There were three main objectives:

1. To determine the extent to which participants in the sample endorsed potential causal and recovery factors as relevant to their ED.
2. To examine the extent (and magnitude) of any ED diagnostic differences in their endorsement of potential causal and recovery factors.
3. To examine the extent (and magnitude) of any differences between recovered and non-recovered participants in their endorsement of potential causal and recovery factors.

Based on the review of current literature, the following hypotheses were proposed:

1. Relative to the other factors examined, the most frequently endorsed potential causal factors would be: low self-esteem, using the ED to help cope with stress or other negative emotions, using the ED to feel a sense of control, feeling pressure to be perfect, a reaction to experiencing trauma, and having been bullied or teased by peers.
2. Relative to the other factors examined, the most frequently endorsed potential recovery factors in treatment would be: a good relationship with the treatment team, being treated as an individual, and tackling the underlying causes of their ED. It was

further hypothesised that support from family, partner and friends would also be highly endorsed as being a factor in recovery.

3. Specific causal factors would also be identified as important factors for recovery. In particular, endorsement of: low self-esteem, using the ED to cope with negative emotions, and using the ED to feel a sense of control; would be positively correlated with endorsement of: an increase in self-esteem, being able to cope with negative emotions in alternative ways, and feeling control over treatment and recovery (respectively).
4. There would be diagnostic variations as follows:
    a) Participants with BN would be more likely to endorse experiencing trauma as a cause of their ED than participants with AN and BED.
    b) Participants with AN and BN would be more likely to perceive that their ED was caused by a need to feel a sense of control than participants with BED.
    c) Participants with AN would be less likely to endorse support groups as a factor that assists in recovery than participants with BN and BED.
    d) Participants with BN and BED would be more likely to endorse tackling issues around body image as a factor that aids recovery than participants with AN.

As existing research in the area is limited, exploratory analyses was also conducted to explore the extent and magnitude of any differences between participants categorised as recovered and non-recovered, in their endorsement of potential causal and recovery factors.

4.2 Method

4.2.1 Study Design

A non-experimental survey design was utilised, with the groups used for analysis derived from self-reported information on ED diagnosis and stage of recovery. Survey research is one of the most commonly used forms of non-experimental research designs. It is used to describe characteristics of a population and to investigate relationships among variables (Edmonds & Kennedy, 2017), consistent with the study objectives. There were a number of advantages to employing a survey in the present study. Using a survey as the mode of data collection allowed for a large sample to be collected and for data to be gathered from participants in a form that allowed for statistical comparison. With the increased use of the internet, using an online survey also provided a number of benefits that were particularly relevant to the current study. The online survey allowed a large number of people to be reached without geographical barriers and at a relatively low cost. Given the sample characteristics, enabling individuals who may feel stigmatised offline and wary of meeting in person to participate anonymously was a further advantage (Wright, 2005). Utilising an online survey for the present study was therefore clearly identified as the most appropriate method.

This study utilised an already existing online survey that was part of the COSTS Study, a collaborative research project run by the University of Otago (see Chapter 1). Based on the key findings from the literature review in relation to the etiology of EDs and factors that are helpful for recovery, both treatment-related and other recovery factors, further items of interest were added to the survey for the purpose of this project (see section 4.2.4 below).

4.2.2 Participants

4.2.2.1 Inclusion and Exclusion Criteria

The participants in this study were a subset of those who took part in the COSTS Study who met the inclusion criteria. Inclusion criteria for the present study were: female, aged 16 years or over, and with a diagnosis of (or probable diagnosis of) anorexia nervosa, atypical anorexia nervosa, bulimia nervosa, subthreshold bulimia nervosa, binge eating disorder, or subthreshold binge eating disorder (DSM-5). Due to the low estimates of people who access specialist ED treatment, as noted in Chapter 2, participants were not required to have experienced treatment. People who completed the online survey who were excluded from the present study were: male, under 16 years of age, those with avoidant restrictive food intake disorder (ARFID), or those who did not report to meet criteria for one of the threshold or subthreshold diagnoses listed above. As established in Chapter 2, females are at a greater risk of an ED than males, therefore it was decided to focus upon the experiences of females. Although males with an EDs are of equal importance, it was anticipated that experiences might differ significantly dependent upon gender, as research has suggested sociocultural messages and the way these messages are internalised can differ between males and females (Lawler & Nixon, 2011; McCabe et al., 2006). Gender differences would have been an additional variable out of the scope of the present thesis. Due to the need to obtain informed consent, participants were required to be 16 years of age and over, as per the ethical approval.

4.2.2.2 Recruitment

Participants were recruited through a number of different methods. Following ethics approval for the amendments to the online survey, the recruitment period lasted 18 months. Being part of a collaborative project meant the communication networks of the different organisations involved could be employed to maximise the reach of recruitment material and therefore participation. Firstly, the internet was used to advertise the study, with details published on the website of the Eating Disorders Association of New Zealand (EDANZ) and sent to their mailing list several times throughout the recruitment period. Social media was utilised by repeatedly posting on the University of Otago, Christchurch ED research Facebook page, community noticeboards and group Facebook pages, ED-related Facebook pages, and student group Facebook pages, as well as the University of Otago Twitter feed. Hard copy posters were also distributed across New Zealand, with tear-off strips that contained the researcher’s contact details and the website address for the survey (a copy is included in Appendix B). The posters were delivered by hand to those locations where it was geographically possible, across Christchurch and Auckland, with locations revisited and posters redisplayed multiple times. Posters were mailed out across the remainder of the country. Locations were targeted that were likely to reach higher proportions of the community or people who were likely to meet the criteria of the study, such as counselling services, medical centres, gyms, university campuses, libraries and supermarkets (detailed in Appendix C). Responses were monitored for the frequency of ED diagnoses.

Approximately two thirds into the data collection period, it was decided to conduct advertising targeted at women with BED, as there were too few responses for this group to allow for a meaningful comparison with AN and BN. The poster was amended to emphasise the definition of binge eating for women who might have experienced BED symptoms but not had a formal diagnosis (see Appendix D). The new poster was displayed in the locations that had previously received the best response, as well as details being posted on the social media pages that had also previously had the best responses (shown in Appendix C). Posters were also displayed at venues hosting weight-related groups such as Overeaters Anonymous, and details posted on Facebook pages related to dieting and weight loss, to try and increase awareness of the research among women with BED (see Appendix C). The approach did increase participation from women with BED, but the BED sample remained lower than AN and BN, so the recruitment period was extended by an extra month to maximise the number of participants in this group.

4.2.3 Procedure

The survey was posted online and all of the recruitment material used throughout contained the link to the website. This allowed all members of the public who thought they met the inclusion criteria for the COSTS Study to complete the survey anonymously and voluntarily at their own convenience. When accessing the link, participants were taken to a page on the University of Otago website that explained the purpose of the study, the researchers involved, the content of the survey, information about confidentiality, and researcher contact details. The link to the survey was at the bottom of the page, beneath a statement advising potential participants that by clicking on the link they were confirming they had read the participant information and were giving their informed consent to participate in the study (a copy of the participant information provided is included in Appendix E). The full survey was estimated to take participants 20 – 30 minutes to complete. To maintain anonymity, participants could add a unique identifier (rather than their name) to their completed survey, so it could be deleted should they later wish to withdraw from the study. Participants were only asked to provide contact details if they were willing to take part in further research.

4.2.4 Measures

The online survey for the COSTS Study collected a range of data using a design based in part on the content of surveys used in two health economics studies for EDs conducted by the Butterfly Foundation in Australia (Deloitte Access Economics, 2012) and the BEAT charity in the U.K. (PricewaterhouseCoopers, 2015), with the required permissions. The survey had been created using research electronic data capture (REDCap), the secure web application software designed to build and manage online databases and surveys (Harris et al., 2009). The COSTS survey had been live online for seven months before amendments were carried out to make the survey more closely aligned with the aims and objectives of the present thesis. This meant therefore that the items added to the survey later on received fewer responses than those which were part of the original survey, so the full sample could be used for the original items but not the additional items. The survey was made up of numerous sections. None of the questions were mandatory, therefore participants were able to leave some survey items blank. Data from the survey used in the present study include demographic information, ED diagnosis, recovery status, treatment history, perceived causes of their ED and perceived factors related to recovery (including factors within and out of treatment).

Demographic data: The demographic data included age, gender, ethnicity and postcode. Responses to age and postcode were in freeform text. Four options were given to choose from for gender: *female*, *male*, *other* and *I prefer not to say*. For ethnicity, participants were presented with nine choices: *New Zealand European, Māori, Samoan, Cook Island Māori*, *Tongan*, *Niuean*, *Chinese*, *Indian* and *other*. If they answered *other*, they were asked to state their ethnic group in freeform text. Participants were able to select more than one ethnicity option.

Eating disorder diagnosis: Participants could complete the survey if they had ever met criteria for an ED, whether or not they had been formally diagnosed or treated. Participants were presented with a list of possible disorders and asked to selected *yes*, *no* or *probable* for each option. The options relevant to this study were: *anorexia nervosa, bulimia nervosa, binge eating disorder, atypical anorexia nervosa, bulimia nervosa – low frequency or short duration,* or *binge eating disorder – low frequency or short duration*. Brief descriptions of core criteria for each disorder were included under each option. The *probable* option allowed people who had not sought professional treatment and therefore had not received a clinical diagnosis to participate. As expected, a number of participants selected *yes* or *probable* for more than one disorder, so the survey also asked “which disorder has been the most significant problem for you?” and this answer was used to determine their diagnostic group for the analyses.

Recovery status: As discussed in Chapter 2, there is no consensus on a single definition of recovery. It was therefore decided to use a self-report measure of recovery status as this better reflected the study focus, which was to take account of the participants' perspective. Recovery status was measured on a 4-point Likert scale: 1 *still have a significant eating disorder*, 2 *still have a significant eating disorder but somewhat improved*, 3 *some symptoms of the eating disorder but overall much improved* and 4 *recovered from the eating disorder*. This scale was taken, with permission, from the survey used by the Butterfly Foundation (Deloitte Access Economics, 2012). For the purpose of analyses here, participants were categorised into two groups. Participants who selected option 1 (*still have a significant eating disorder*) or 2 (*still have a significant eating disorder but somewhat improved*) were merged to create a *non-recovered* category. Participants who selected option 3 (*some symptoms of the eating disorder but overall much improved*) or 4 (*recovered from the eating disorder*) were merged to form a *recovered* category.

Treatment: Firstly, participants were asked to describe their treatment pathway (frequency of treatment over the course of their illness) by selecting from six options, one of which was *no treatment*, and this was used in the present study to distinguish participants who had not experienced any treatment. For those who had experienced treatment, a list of possible treatments was given, alongside a tick box for each option, with the instruction to "check all that apply", to determine which treatments had been experienced (see Table 2). This meant participants were able to check multiple options.

Causes of the ED: To collect the participants' views on the etiology of their ED, the survey set out a list of 15 potential causes based on a literature review, with a 4-point Likert scale: 1 *not a reason*, 2 *probably not a reason*, 3 *to some extent a reason* and 4 *definitely a major reason*. The items were presented in a set order. The Reasons for Depression Questionnaire (RFD) was used as a model for item structure and scale format in the design of the original COSTS Study. The RFD measures clients' own beliefs about the causes of their depression (Addis et al., 1995).

Selected based on the literature review, the survey items used in the present study that were part of the original COSTS survey were: "I was bullied or teased about my weight or appearance", "I was bullied or teased about other things", "I had low self-esteem", "it is a biological or genetic illness", "I felt pressure to be thin", "certain issues that happened to me as a child", "I was having difficulty coping with major life changes", "there was conflict with key people in my life" and "there was no-one to share my innermost thoughts and feelings with". Three new items were developed by the researcher (RW) to address additional key constructs that emerged from the literature review: "it helped me cope when feeling stress or other negative emotions", "a reaction to traumatic life event(s) or experience(s)" and "certain aspects of my personality made me more susceptible". Two items were also amended to better reflect the findings from the literature review. 'I felt pressure to succeed' was extended to "I felt pressure to succeed and be perfect" to incorporate the factor of perfectionism. 'I wanted to get control of my life' was amended to "it made me feel a sense of control in my life". In addition, an option of "I don't know why I developed an eating disorder" was given. These new and amended items were added to the survey following ethics approval.

Factors related to recovery*:* To determine perceived factors related to recovery, participants were given a set order list of 17 potential contributors to recovery, with the instruction: "If you have recovered or improved, please indicate the extent to which you think the following factors assisted in your recovery process". Participants were presented with a 4-point Likert scale to rate each option as: 1 *not a factor*, 2 *probably not a factor*, 3 *to some extent a factor* or 4 *definitely an important factor*. The original survey consisted of eight items that remained in this study: "own motivation", "family/partner involvement in treatment", "support groups/organisations", "good relationship with treatment team", "new relationship", “new direction in education or new job”, “having a child” and “changing another important aspect of life”. Following ethics approval, eight new items were added based on the literature review and to meet the objectives of the study: “medication”, “specific aspect of treatment”, “tackling issues around food and body image”, “tackling underlying causes”, “having some control over my treatment and recovery”, “being treated as an individual”, “increase in self-esteem”, and “able to express and cope with negative emotions in alternative ways”. Finally, two original items, ‘family/partner support’ and ‘support of friends’, were merged into one item: “family/partner/friends support”. A copy of the section of the online survey relating to causal and recovery factors, as described above, is provided in Appendix F. A copy of the full survey is available on request from the University of Otago.

4.2.5 Data Analyses

Using the REDCap online data collection tool allowed the data from the online survey to be exported in a csv format that could then be imported into IBM SPSS Statistics version 25 for analysis. Firstly, frequency tables were created to determine the number and percentage of participants who endorsed each potential causal and recovery factor. Normality of the data was examined by calculating the skewness and conducting a visual inspection of a histogram for each item (see Appendix G). Box plots for each item were used to test for any outliers or errors. The 5% trim mean did not largely vary from the mean for any of these items therefore no corrections or exclusions had to be made.

For the purpose of ranking the factors in order of their level of endorsement and for the regression analyses, scores on the 4-point Likert scale for each potential causal factor and potential recovery factor were transformed into a dichotomous variable. The data was transformed by merging all of the responses of 1 (*not a reason* or *not a factor*) or 2 (*probably not a reason* or *probably not a factor*) into a *not a reason* category (*not a factor* for recovery factors), and the responses of 3 (*to some extent a reason* or *to some extent a factor*) or 4 (*definitely a major reason* or *definitely an important factor*) into a *a reason* category (*a factor* for recovery factors). Dichotomising the responses allowed the factors to be ranked based upon the percentage of participants who responded that the factor was *a reason* (or *a factor*) and maximised the number of responses in each category for analyses.

Pearson's *r* or Spearman's rho tests, dependent upon the normality of the distribution, were conducted between each of the potential causal factors, and between each of the potential recovery factors, to identify the extent of correlations between factors. Cohen (1992)'s guidelines on correlation coefficients were used to interpret the magnitude of correlations where > .1 is weak, > .3 is moderate and > .5 is large. For each of the factors that featured both as a potential causal and recovery factor (self-esteem, coping with negative emotions, and control), Spearman's rho correlations were conducted to examine the relationship between the corresponding causal factor and recovery factor.

To examine any diagnostic differences in the survey responses to each potential causal and recovery factor, the sample were categorised into three diagnostic groups (AN, BN and BED). Participants who responded with *yes* or *probable* to a diagnosis of "anorexia nervosa" or "atypical anorexia" were grouped into AN; "bulimia nervosa" or "bulimia nervosa – low frequency or short duration" (subthreshold BN) into BN; and "binge eating disorder" or "binge eating disorder – low frequency or short duration" (subthreshold BED) into BED. As previously explained, for participants who selected *yes* or *probable* for more than one disorder, the answer to the survey question "which disorder has been the most significant problem for you?" was used to determine their diagnostic group.

Across the three diagnostic groups, analysis of variance (ANOVA) and Kruskal-Wallis tests were conducted (dependent on distribution) for the 4-point Likert scale responses to each potential causal and recovery factor. Multinomial regression was then used to further investigate any diagnostic differences by examining the relative contribution of the potential causal and recovery factors in predicting ED diagnosis using the dichotomised responses. First, the predictor variables identified through the univariate analysis were added to the model. Next, the covariates of age, age of onset and duration of ED were added; this adjusted model was compared to the crude model to determine if they had any confounding impact.

For the recovery status analyses, t-tests and Mann-Whitney U tests (dependent on normality of the distribution) were conducted for the 4-point Likert scale responses to each potential causal and recovery factor. Binary logistic regression was used to examine the relative contribution of the potential causal and recovery factors in predicting recovery status using the dichotomised responses, to further explore factors that may influence recovery. As with the multinomial regression, this was conducted in two stages. As previously explained, participants were separated into two categories for the analysis; a recovered and a non-recovered category. Creating just two categories for recovery status maximised the number of participants in each category for analyses. The recovered category consisted of those who responded that they were either recovered or much improved. This decision was made due to, as detailed in Chapter 2, the fact that women with a history of an ED sometimes perceive recovery as something that will always be an ongoing process (Federici & Kaplan, 2008) and may be ambivalent towards the concept of full recovery (Darcy et al., 2010). From this point, the term ‘recovered category’ will refer to the group of women who have self-reported that they have reached either full recovery, or partial recovery with significant improvements.

An alpha level of .05 was used for all statistical tests. For ease of interpretation, means and standard deviations are presented in the results tables for all statistical comparison tests, however, the statistics reported for the Kruskal-Wallis and Mann-Whitney U tests were calculated using mean ranks (detailed in the text for the statistically significant results). A hierarchical approach was taken for the regression models with a lenient threshold of $\leq .10$

used to determine the potential univariate variables that were entered into the regression models. An assessment of the final model was based on an alpha level of .05.

4.3 Results

4.3.1 Summary of Participants

Demographics: The sample consisted of 364 women (*n* = 111 before the survey was amended; *n* = 253 after the survey was amended). Demographic information for the sample is presented in Table 1. The mean age was 28.2 years (*SD* = 12.2), with an age range of 16 to 77 years old. With regard to ethnicity, the sample consisted of 88.7% New Zealand European (*n* = 323), 6% Maori (*n* = 22), 1.1% Pasifika (*n* = 4) and 13.2% (*n* = 48) ‘other’ ethnicity, which included Chinese, European, Australian, Middle Eastern and Indian.

Eating disorder characteristics: ED characteristics of the sample are also presented in Table 2. The mean age of onset of first ED symptoms was 15.2 years old (*SD* = 4.7) and the mode was 14 years old. The mean duration of illness (disregarding participants who did not provide a value) was 9.0 years (*SD* = 8.0). The sample comprised: 60.5% with AN (*n* = 220), of whom 9.6% (*n* = 21) reported a probable diagnosis; 28% with BN (*n* = 102), of which 12.8% (*n* = 13) reported a probable diagnosis; and 11.5% with BED (*n* = 42), of which 33.3% (*n* = 14) reported a probable diagnosis. Therefore, 86.8% of the total sample reported a full diagnosis and 13.2% reported a probable diagnosis.

In terms of recovery, 53.6% were in the recovered category (*n* = 195) and 46.4% were in the non-recovered category (*n* = 169). There was no statistically significant difference between participants in the recovered category and non-recovered category in terms of their current age (*t*(362) = -1.74, *p* = .08) or age of onset of their first ED symptoms (*t*(353) = 1.15, *p* = .25).

Table 1

Demographics, diagnosis, and clinical characteristics of the total sample, and by recovered and non-recovered categories

	Total **(*N* = 364)**	**Recovered** **(*n* = 195)**	**Non-recovered** **(*n* = 169)**
Age (years)			
M (SD)	28.2 (12.2)	29.2 (12.6)	27.0 (11.7)
Range	16 – 77	16 – 66	16 – 77
Ethnicity % (*n*)*			
New Zealand European	88.7 (323)	90.3 (176)	87.0 (147)
Māori	6.0 (22)	4.6 (9)	7.7 (13)
Pasifika	1.1 (4)	1.5 (3)	0.6 (1)
Other	13.2 (48)	12.3 (24)	14.2 (24)
Diagnostic group % (*n*)			
AN	60.5 (220)	61.5 (120)	59.2 (100)
BN	28.0 (102)	30.3 (59)	25.4 (43)
BED	11.5 (42)	8.2 (16)	15.4 (26)
Age of onset of first ED symptoms			
M (SD)	15.2 (4.7)	14.9 (4.4)	15.5 (5.0)
Range	4 – 50	5 – 48	4 – 50
Duration of ED symptoms (years)**			
M (SD)	9.0 (8.0)	8.1 (7.0)	11.0 (9.8)
Range	0.5 – 50	1 – 38	0.5 – 50

Note. *participants were able to select more than one option. **Consisting of 232 responses, disregarding participants who did not provide a value (non-recovered=71, recovered=161).

Treatment experience: In terms of treatment, 80.3% (n = 289) reported receiving some form of treatment. Data on the treatment experiences of the sample, broken down by diagnosis, is set out in Table 2. The most common forms of treatment were *cognitive behavioural therapy* (51.7%), *family-based therapy* (26.6%), *group therapy* (19.2%) and *dialectical behaviour therapy* (15.7%). For the *other therapy type* category (13.5%) participants reported receiving narrative therapy, individual psychotherapy, acceptance and commitment therapy, MANTRA, and non-specific counselling. Some participants, however, did not know the name of their treatment (20.1%) and 19.5% of participants had not received any treatment (n = 71). There were several statistically significant differences between diagnostic groups in terms of their treatment experiences. Family-based therapy was more frequently experienced by participants with AN than BN ($\chi^2(1,322) = 23.8$, $p < .001$) and BED ($\chi^2(1,262) = 12.3$, $p < .001$), and dialectical behaviour therapy was more frequently experienced by participants with AN than BN ($\chi^2(1,322) = 7.19$, $p = .007$) and BED ($\chi^2(1,262) = 6.15$, $p = .01$). Cognitive behavioural therapy was more frequently experienced by participants with AN than BED ($\chi^2(1,262) = 5.51$, $p = .02$). Psychodynamic treatment was more frequently experienced by participants with BED than BN ($\chi^2(1,144) = 8.61$, $p = .003$). Participants with BN reported not knowing the name of the treatment more often than AN ($\chi^2(1,322) = 6.05$, $p = .01$) and BED ($\chi^2(1,144) = 11.1$, $p = .001$), and participants with AN more than participants with BED ($\chi^2(1,262) = 4.72$, $p = .03$).

Table 2

Type of treatment(s) received by the total sample and by diagnostic groups

	Total **% (*n*)**	**AN** **% (*n*)**	**BN** **% (*n*)**	**BED** **% (*n*)**
Treatment*				
Family-based therapy	26.6 (97)	37.3 (82)	10.8 (11)	9.5 (4)
Cognitive behavioural therapy	51.7 (188)	55.5 (122)	50.0 (51)	35.7 (15)
Dialectical behaviour therapy	15.7 (57)	20.9 (46)	8.8 (9)	4.8 (2)
Specialist supportive clinical management	3.3 (12)	3.6 (8)	2.0 (2)	4.8 (2)
Psychodynamic	6.9 (25)	7.7 (7)	2.0 (2)	14.3 (6)
Interpersonal therapy	5.5 (20)	7.3 (16)	2.0 (2)	4.8 (2)
Cognitive remediation	2.5 (9)	2.7 (6)	2.0 (2)	2.4 (1)
Metacognitive therapy	2.2 (8)	2.7 (6)	2.0 (2)	0.0
Group therapy	19.2 (70)	22.3 (49)	16.7 (17)	9.5 (4)
Other therapy type	13.5 (49)	11.4 (25)	18.6 (19)	11.9 (5)
I don't know the name of the therapy	20.1 (73)	18.2 (40)	30.4 (31)	4.8 (2)
No Treatment	19.5 (71)	11.8 (26)	25.5 (26)	45.2 (19)

Note. *Participants were able to select more than one option.

4.3.2 Perceived Causal Factors of EDs

The responses from participants for all of the potential causal factors are set out in Table 3 (the findings directly related to the hypotheses are in bold). In partial support of Hypothesis 1 (that relative to the other potential causal factors examined, the most frequently endorsed factors will be: low self-esteem, using their ED to help cope with stress or other negative emotions, using their ED to feel a sense of control and feeling pressure to be perfect), the potential causal factors participants most frequently endorsed were: “I had low self-esteem” (93.3%, ranked #1), “it helped me cope when feeling stress or other negative emotions” (90.8%, ranked #2), “I felt pressure to succeed and be perfect” (82.9%, ranked #3), and “it made me feel a sense of control in my life” (82.3%, ranked #4).

Contrary to the latter part of Hypothesis 1 (a reaction to experiencing trauma, and having been bullied or teased by peers will also be among the most frequently endorsed factors), the other three potential causes hypothesised to be highly endorsed, although endorsed by around half of the sample, were much lower in the rankings: “a reaction to traumatic life event(s) or experience(s)” was endorsed by 52.7% (ranked #9), “I was bullied or teased about my weight or appearance” was endorsed by 52.0% (ranked #10), and “I was bullied or teased about other things” was endorsed by 43.1% (ranked #14).

Another potential causal factor that was highly endorsed was “I felt pressure to be thin” (81.3%, ranked #5). The great majority of participants made specific causal attributions for their ED, with “I don’t know why I developed an eating disorder” being the least endorsed item on the survey (31.0%).

Table 3

Number and percentage of each potential causal factor endorsed as either 'a reason' or 'not a reason' for their ED

Causal Factor	**Total Partici-pants (*N*)**	**A Reason % (*n*)**	**Not a Reason % (*n*)**	**Rank**
I had low self-esteem	358	93.3 (334)	6.7 (24)	1
It helped me cope when feeling stress or other negative emotions	249*	90.8 (226)	9.2 (23)	2
I felt pressure to succeed and be perfect	246*	82.9 (204)	17.1 (42)	3
It made me feel a sense of control in my life	248*	82.3 (204)	17.7 (44)	4
I felt pressure to be thin	358	81.3 (291)	18.7 (67)	5
Certain aspects of my personality made me more susceptible	246*	79.7 (196)	20.3 (50)	6
I was having difficulty coping with major life changes	354	67.5 (239)	32.5 (115)	7
There was no-one to share my innermost thoughts and feelings with	358	62.6 (224)	37.4 (134)	8
A reaction to traumatic life event(s) or experience(s)	245*	52.7 (129)	47.3 (116)	9
I was bullied or teased about my weight or appearance	356	52.0 (185)	48.0 (171)	10
There was conflict with key people in my life	358	51.7 (185)	48.3 (173)	11
Certain issues that happened to me as a child	355	51.3 (182)	48.7 (173)	12
It is a biological or genetic illness	351	46.4 (163)	53.6 (188)	13
I was teased or bullied about other things	355	43.1 (143)	56.9 (202)	14
I don't know why I developed an ED	258*	31.0 (80)	69.0 (178)	15

Note. *New item added to the survey so not completed by the full sample.

4.3.2.1 Correlation Analyses Among Potential Causal Factors

Correlation analyses were conducted to examine the association between each of the potential causal factors (see Table 4). There was one large magnitude positive correlation: “a reaction to traumatic life event(s) or experience(s)” was strongly correlated with “there was conflict with key people in my life” ($r = .52$, $p < .001$). Several factors were moderately correlated with multiple other factors: “It helped me cope when feeling stress or other negative emotions” was positively correlated with “I was having difficulty coping with major life changes” ($r_s = .35$, $p < .001$), “there was no-one to share my innermost thoughts and feelings with” ($r_s = .33$, $p < .001$), and “it made me feel a sense of control in my life” ($r_s = .37$, $p < .001$). “It made me feel a sense of control in my life” also had a moderate positive correlation with “certain aspects of my personality made me more susceptible” ($r_s = .31$, $p < .001$) and “I felt pressure to succeed and be perfect” ($r_s = .35$, $p < .001$). “I felt pressure to succeed and be perfect” had a further moderate positive correlation with “certain aspects of my personality made me more susceptible” ($r_s = .41$, $p < .001$) and “I felt pressure to be thin” ($r_s = .43$, $p < .001$). Finally, in addition to “it helped me cope when feeling stress or other negative emotions”, “I was having difficulty coping with major life changes” had a moderate positive correlation with “there was conflict with key people in my life” ($r_s = .44$, $p < .001$) and “a reaction to traumatic life event(s) or experience(s)” ($r_s = .43$, $p < .001$).

Table 4

Correlation matrix of relationships among potential causal factors, with coefficient and significance for each factor

Factor	**1[b]**	**2[b]**	**3[b]**	**4[b]**	**5[b]**	**6[b]**	**7[b]**	**8[b]**	**9[a]**	**10[a]**	**11[a]**	**12[a]**	**13[a]**
1. I had low self-esteem[b]	-												
2. It helped me cope when feeling stress or other negative emotions[b]	.19 .003*	-											
3. I felt pressure to succeed and be perfect[b]	.19 .002*	.22 .001*	-										
4. It made me feel a sense of control in my life[b]	.22 <.001*	.37 <.001*	.35 <.001*	-	.								
5. I felt pressure to be thin[b]	.29 <.001*	.16 .01**	.43 <.001*	.07 .27	-								
6. Certain aspects of my personality made me more susceptible[b]	.17 .008*	.19 .003*	.41 <.001*	.31 <.001*	.21 .001*	-							
7. I was having difficulty coping with major life changes[b]	.06 .27	.35 <.001*	.11 .10	.14 .03**	.08 .13	.19 .003*	-						
8. There was no-one to share my innermost thoughts and feelings with[b]	.20 <.001*	.33 <.001*	.11 .09	.08 .23	.24 <.001*	.11 .08	.28 <.001*	-					
9. A reaction to traumatic life event(s) or experience(s)[a]	-.01 .94	.15 .02**	-.05 .48	.11 .09	-.11 .08	.03 .65	.43 <.001*	.26 <.001*	-				
10. I was bullied or teased about my weight or appearance[a]	.18 .001*	.02 .77	.17 .008*	-.06 .38	.28 <.001*	-.01 .94	.08 .12	.12 .03**	.06 .34	-			
11. There was conflict with key people in my life[a]	.03 .60	.22 <.001*	.02 .73	.08 .23	.05 .33	.07 .30	.44 <.001*	.41 <.001*	.52[†] <.001*	.14 .008*	-		
12. Certain issues that happened to me as a child[a]	.09 .10	.22 .001*	-.02 .78	.04 .52	.10 .05	.06 .38	.22 <.001*	.30 <.001*	-.13 .04**	.13 .01**	.04 .50	-	
13. It is a biological or genetic illness[a]	.05 .33	.12 .06	.16 .01**	.14 .03**	.03 .53	.29 <.001*	.10 .07	.05 .36	.05 .44	.13 .02**	.01 .86	.05 .33	-
14. I was teased or bullied about other things[a]	.28 <.001*	.02 .79	.10 .10	.01 .83	.14 .01**	.15 .02**	.20 <.001*	.23 <.001*	.15 .02**	.49 <.001*	.26 <.001*	.27 <.001*	.06 .25

Note. * = Statistically significant at level *p* <.01. ** = Statistically significant at level *p* <.05. [†] = large correlation at >.5. [a] = Pearson's *r* for normal distribution. [b] = Spearman's rho.

4.3.3 Perceived Recovery Factors for EDs

The responses from participants for all of the potential factors related to recovery can be found in Table 5 (the findings directly related to the hypotheses are in bold). Of the participants who reported they *still have a significant eating disorder*, 28.4% (*n* = 23) did not respond to the section of the survey on factors in recovery, therefore not all participants completed this section of the survey.

There was partial support for Hypothesis 2 (that relative to the other potential recovery factors examined, the most frequently endorsed factors in treatment would be: a good relationship with the treatment team, being treated as an individual, and tackling the underlying causes of their ED). “Tackling underlying causes” was the second most frequently endorsed potential recovery factor (69.4%, ranked #2). The other two factors hypothesised to be highly endorsed by participants were actually lower in the rankings than expected. These two factors were only endorsed by just over half of participants: “being treated as an individual” was endorsed by 59.3% (ranked #7) and “good relationship with treatment team” was endorsed by 51.6% (ranked #9). Consistent with the second part of Hypothesis 2 (that support from family, partner and friends will also be highly endorsed as being a factor in recovery) over two thirds of participants (69.1%, ranked #3) endorsed “family/partner/friends support” as a recovery factor.

Additionally, the most highly endorsed potential recovery factor was “own motivation” (87.9%). Although the support of family, partner and friends was highly endorsed as a recovery factor, “family/partner involvement in treatment” (47.0%, ranked #10) and “support groups/organisations” (25.2%, ranked #15) were ranked much lower.

Table 5

Number and percentage of each potential recovery factor endorsed as 'a factor' or 'not a factor' in recovery from or improvement of their ED

Recovery Factor	**Total Partici-pants (*N*)**	**A Factor % (*n*)**	**Not a Factor % (*n*)**	**Rank**
Own motivation	330	87.9 (290)	12.1 (40)	1
Tackling underlying causes	216*	69.4 (150)	30.6 (66)	2
Family/partner/friends support	220*	69.1 (152)	30.9 (68)	3
Tackling issues around food and body image	217*	66.4 (144)	33.6 (73)	4
Able to express and cope with negative emotions in alternative ways	216*	64.4 (139)	35.6 (77)	5
Having some control over my treatment and recovery	216*	64.4 (139)	35.6 (77)	5
Being treated as an individual	214*	59.3 (127)	40.7 (87)	7
Increase in self-esteem	217*	55.3 (120)	44.7 (97)	8
Good relationship with treatment team	322	51.6 (166)	48.4 (156)	9
Family/partner involvement in treatment	328	47.0 (154)	53.0 (174)	10
New direction in education or new job	326	39.3 (128)	60.7 (198)	11
Medication	219*	36.5 (80)	63.5 (139)	12
Specific aspect of treatment	207*	36.2 (75)	63.8 (132)	13
Changing another important aspect of life	321	34.0 (109)	66.0 (212)	14
Support groups/organisations	325	25.2 (82)	74.8 (243)	15
New relationship	325	23.4 (76)	76.6 (249)	16
Having a child	321	9.3 (30)	90.7 (291)	17

Note. *New item added to the survey so not completed by the full sample.

4.3.3.1 Correlation Analyses Among Potential Recovery Factors

A correlation analyses was used to investigate the association among the potential recovery factors. Correlation analyses indicated that many of the potential recovery factors were correlated with each other at a statistically significant level (see Table 6). There were four large magnitude positive correlations, which were: “family/partner involvement in treatment” with “family/partner/friends support” ($r_s = .52$, $p < .001$), “being treated as an individual” with “good relationship with treatment team” ($r = .65$, $p < .001$), “being treated as an individual” with “having some control over my treatment and recovery” ($r_s = .62$, $p < .001$), and “able to express and cope with negative emotions in alternative ways” with “increase in self-esteem” ($r_s = .59$, $p < .001$). In addition to the two large correlations noted above, “being treated as an individual” was also moderately positively correlated with “tackling underlying causes” ($r_s = .46$, $p < .001$).

Several other factors had moderate positive correlations with multiple other factors. In addition to being correlated with “being treated as an individual”, “good relationship with treatment team” was moderately positively correlated with “medication” ($r_s = .45$, $p < .001$), “specific aspect of treatment” ($r_s = .47$, $p < .001$), and “tackling underlying causes” ($r_s = .45$, $p < .001$). Furthermore, “tackling underlying causes” was also had a moderate positive correlation with “having some control over my treatment and recovery” ($r_s = .47$, $p < .001$), “increase in self-esteem” ($r_s = .42$, $p < .001$) and “able to express and cope with negative emotions in alternative ways” ($r_s = .49$, $p < .001$).

Table 6

Correlation matrix of relationships among potential recovery factors, with coefficient and significance for each factor

	1^{b}	**2^{b}**	**3^{b}**	**4^{b}**	**5^{b}**	**6^{b}**	**7^{a}**	**8^{a}**	**9^{a}**	**10^{a}**	**11^{b}**	**12^{b}**	**13^{b}**	**14^{b}**	**15^{b}**	**16 ^{b}**
1. Own motivation^{b}	-															
2. Tackling underlying causes^{b}	.23 .001*	-														
3. Family/partner/friends support^{b}	.10 .16	.18 .008*	-													
4. Tackling issues around food and body image^{b}	.24 <.001*	.36 <.001*	.12 .07	-												
5. Able to express and cope with negative emotions in alternative ways^{b}	.24 <.001*	.49 <.001*	.21 .002*	.26 .000*	-											
6. Having some control over my treatment and recovery^{b}	.32 <.001*	.47 <.001*	.19 .006*	.33 <.001*	.35 <.001*	-										
7. Being treated as an individual^{a}	.20 .003*	.46 <.001*	.33 <.001*	.27 <.001*	.39 <.001*	.62† <.001*	-									
8. Increase in self-esteem^{a}	.29 <.001*	.42 <.001*	.13 .06	.26 <.001*	.59† <.001*	.28 <.001*	.36 <.001*	-								
9. Good relationship with treatment team^{a}	.10 .07	.45 <.001*	.36 <.001*	.31 <.001*	.30 <.001*	.34 <.001*	.65† <.001*	.20 .004*	-							
10. Family/ partner involvement in treatment^{a}	-.07 .20	-.03 .65	.52† <.001*	.05 .51	.05 .50	.01 .85	.22 .001*	.00 .99	.29 <.001*	-						
11. New direction in education or new job^{b}	.09 .12	.23 .001*	.12 .07	.18 .007*	.14 .04**	.23 .001*	.18 .009*	.25 <.001*	.09 .09	.14 .01**	-					
12. Medication^{b}	.02 .73	.25 <.001*	.19 .005*	.18 .008*	.08 .27	.19 .006*	.27 <.001*	.05 .46	.45 <.001*	.26 <.001*	.13 .07	-				
13. Specific aspect of treatment^{b}	.08 .24	.27 <.001*	.16 .02**	.22 .001*	.12 .09	.23 .001*	.39 <.001*	-.00 .97	.47 <.001*	.17 .01**	.03 .64	.27 <.001*	-			
14. Changing another important aspect of life^{b}	.10 .09	.30 <.001*	.10 .15	.16 .02**	.38 <.001*	.30 <.001*	.21 .002*	.37 <.001*	-.06 .93	.01 .88	.39 <.001*	-.02 .75	.06 .38	-		
15. Support groups/organisations^{b}	.12 .04**	.27 <.001*	.22 .001*	.23 .001*	.27 <.001*	.23 .001*	.35 <.001*	.22 .001*	.38 <.001*	.17 .002*	.16 .003*	.34 <.001*	.42 <.001*	.15 .009*	-	
16. New relationship^{b}	.05 .41	.05 .46	.20 .004*	.17 .01**	.12 .07	.11 .11	.21 .002*	.23 .001*	.12 .04**	.19 .001*	.39 <.001*	.10 .13	-.03 .65	.18 .001*	.12 .03**	-
17. Having a child^{b}	.05 .42	.05 .50	-.07 .28	-.11 .12	.03 .68	-.05 .50	-.05 .50	.14 .04**	-.11 .05	.01 .84	.06 .31	-.02 .81	-.09 .19	.16 .005*	.08 .17	.12 .04**

Note. * = Statistically significant at level $p < .01$. ** = Statistically significant at level $p < .05$. † = large correlation at >.5. ^{a} = Pearson's r for normal distribution. ^{b} = Spearman's rho.

4.3.4 Relationships Between Causal and Recovery Factors in EDs

To examine Hypothesis 3, that endorsement of certain causal factors would be positively correlated with endorsement of addressing those same factors for recovery, the factors that spanned causes and recovery (self-esteem, control and coping with negative emotions) were analysed in relation to one another. Spearman's rho analyses indicated there was no statistically significant correlation between "I had low self-esteem" and 'increase in self-esteem", (r_s = .01, p = .15), or "it made me feel a sense of control in my life" and "having some control over my treatment and recovery" (r_s = .04, p = .55). There was a statistically significant but weak correlation between endorsement of "it helped me cope when feeling stress or other negative emotions" as a cause of their ED and endorsement of "able to express and cope with negative emotions in alternative ways" as a factor in recovery (r_s = .19, p = .007).

4.3.5 Comparison of Causal and Recovery Factors Among ED Diagnostic Groups

4.3.5.1 Potential Causal Factors

It was hypothesised that there would be diagnostic variations in participants' endorsement of potential causal factors, specifically: participants with BN would be more likely to endorse experiencing trauma as a causal factor than AN and BED groups (Hypothesis 4a), and participants with AN and BN would be more likely to endorse feeling a sense of control from their ED as a causal factor (Hypothesis 4b). The results of ANOVA (with post-hoc Tukey HSD tests) or Kruskal-Wallis tests (with post-hoc pairwise comparison tests) are presented in Table 7. As previously explained in section 4.2.5, means and standard deviations are presented in the table, however the statistics reported for the Kruskal-Wallis tests were calculated using mean ranks (detailed in the text for the statistically significant results).

As hypothesised, endorsement of the potential causal factor “it made me feel a sense of control in my life” was significantly higher for participants with AN than participants with BN and BED, and significantly higher for BN than BED (mean rank of 142 for AN, 118 for BN and 69 for BED). Contrary to the hypothesis, participants with BN did not differ significantly from the other diagnostic groups in their response to the item “a reaction to traumatic life event(s) or experience(s)”.

Other potential causal factors were found to vary dependent on ED diagnosis. Reponses to “I don’t know why I developed an ED” differed significantly between each diagnostic group (mean rank score of 165 for BED, 130 for AN and 111 for BN). There were three other potential causal factors where the AN group differed significantly from one or both of the other diagnostic groups. Participants with AN endorsed the factor “it is a biological or genetic illness’ to a greater extent than participants with BN, and endorsed “certain aspects of my personality made me more susceptible” to a greater extent than participants with BED (mean rank of 133 for AN compared with 106 for BED). The factor “I was bullied or teased about my weight or appearance” was endorsed to a lesser extent by participants with AN than participants with BED and BN.

Table 7

Comparison of participants' endorsement of each potential causal factor, based on ED diagnostic group (AN, BN and BED)

Causal Factor	**AN** ***M* (*SD*)** **($n = 220$)**	**BN** ***M* (*SD*)** **($n = 102$)**	**BED** ***M* (*SD*)** **($n = 42$)**	***H or F***†	***p***
I had low self-esteem	3.49 (0.70)	3.52 (0.64)	3.44 (0.92)	$H = .16$	.92
It helped me cope when feeling stress or other negative emotions	3.44 (0.87)	3.55 (0.74)	3.67 (0.74)	$H = 2.82$	.25
I felt pressure to succeed and be perfect	3.38 (1.00)	3.40 (0.92)	3.08 (1.06)	$H = 4.18$	.12
It made me feel a sense of control in my life	**3.65 (0.75)**	**3.33 (0.91)**	**2.33 (1.29)**	**$H = 41.7$**	**<.001*** **AN > BN > BED‡**
I felt pressure to be thin	3.09 (1.00)	3.35 (0.78)	3.29 (0.93)	$H = 4.53$	.10
Certain aspects of my personality made me more susceptible	3.24 (0.88)	2.99 (0.99)	2.89 (0.92)	$H = 6.62$	.04** AN > BED‡
I was having difficulty coping with major life changes	2.90 (1.02)	2.87 (1.11)	3.15 (1.14)	$H = 3.30$	.19
There was no-one to share my innermost thoughts and feelings with	2.68 (1.10)	2.81 (1.09)	3.00 (0.95)	$H = 3.19$	.20
A reaction to traumatic life event(s) or experience(s)	**2.58 (1.22)**	**2.69 (1.23)**	**2.50 (1.21)**	**$F = .35$**	**.70**
I was bullied or teased about my weight or appearance	2.15 (1.05)	2.65 (1.07)	3.00 (1.03)	$F = 15.3$	<.001* AN < BED‡ AN < BN‡
There was conflict with key people in my life	2.46 (1.16)	2.58 (1.22)	2.80 (1.25)	$F = 1.55$	.21
Certain issues that happened to me as a child	2.42 (1.21)	2.73 (1.15)	2.63 (1.30)	$F = 2.42$	.09
It is a biological or genetic illness	2.44 (1.06)	1.90 (0.99)	2.15 (1.11)	$F = 9.36$	<.001* AN > BN‡
I was teased or bullied about other things	2.13 (1.08)	2.23 (1.00)	2.55 (1.15)	$F = 2.61$	.08
I don't know why I developed an ED	1.85 (1.12)	1.53 (0.93)	2.44 (1.26)	$H = 15.2$	<.001* BED > AN > BN‡

Note. * = Statistically significant at level $p < .01$. ** = Statistically significant at level $p < .05$.
†ANOVA test (F) for normal distribution or Kruskal-Wallis test (H). ‡ Determined using post-hoc test.

4.3.5.2 Potential Recovery Factors

Comparisons between the diagnostic groups were conducted for all of the potential recovery factors (see Table 8). These analysis was completed by using ANOVA (with post-hoc Tukey HSD tests) and Kruskal-Wallis H tests (with post-hoc pairwise comparison tests). As previously explained in section 4.2.5, means and standard deviations are presented in the table, however the statistics reported for the Kruskal-Wallis tests were calculated using mean ranks (detailed in the text for the statistically significant results).

There was partial support for Hypothesis 4c, (that participants with AN would be less likely to endorse support groups as a factor that assists in recovery). Participants with BED endorsed the factor “support groups/organisations” to a significantly greater extent than both AN and BN (mean rank for BED of 203, compared to 146 for BN and 165 for AN). Similarly, in partial support of Hypothesis 4d, (that participants with BN and BED would be more likely to endorse tackling issues around body image as a factor that aids recovery), participants with BED also endorsed “tackling issues around food and body image” to a greater extent than participants with both AN and BN (mean rank for BED of 140 compared with 104 for AN and 106 for BN). Participants with BN did not differ from participants with AN in endorsement of either of these factors.

For the other potential recovery factors, there were four statistically significant differences among ED diagnostic groups. The factor “family/partner involvement in treatment” was endorsed to a greater extent by participants with AN than BN, and “good relationship with treatment team” was endorsed to a greater extent by participants with AN than BED. The factor “family/partner/friends support” was endorsed to a lesser extent by participants with BN than both AN and BED (mean rank of 93 for BN compared with 116 for AN and 127 for BED).

Table 8

Comparison of participants' endorsement of each potential recovery factor, based on ED diagnostic group (AN, BN and BED)

Causal Factor	**AN** ***M*** **(*SD*)** **(*n* = 220)**	**BN** ***M*** **(*SD*)** **(*n* = 102)**	**BED** ***M*** **(*SD*)** **(*n* = 42)**	***H or F*†**	***p***
Own motivation	3.37 (0.85)	3.51 (0.77)	3.37 (0.89)	*H* = 1.93	.38
Tackling underlying causes	2.89 (1.09)	2.91 (1.19)	3.16 (1.11)	*H* = 1.66	.44
Family/partner/friends support	2.91 (1.09)	2.49 (1.17)	3.07 (1.11)	*H* = 8.51	.01** BN < BED‡ BN < AN‡
Tackling issues around food and body image	**2.73 (1.05)**	**2.74 (1.13)**	**3.32 (0.99)**	***H* = 7.73**	**.02**** **BED > BN‡** **BED > AN‡**
Able to express and cope with negative emotions in alternative ways	2.69 (1.09)	2.68 (1.18)	3.08 (1.02)	*H* = 2.82	.25
Having some control over my treatment and recovery	2.81 (1.15)	2.59 (1.24)	3.04 (1.17)	*H* = 2.96	.23
Being treated as an individual	2.79 (1.25)	2.53 (1.34)	2.64 (1.29)	*F* = .88	.42
Increase in self-esteem	2.44 (1.08)	2.79 (1.07)	2.35 (1.16)	*F* = 2.68	.07
Good relationship with treatment team	2.61 (1.22)	2.35 (1.32)	2.00 (1.18)	*F* = 3.56	.03** AN > BED‡
Family/partner involvement in treatment	2.50 (1.16)	2.06 (1.16)	2.17 (1.18)	*F* = 4.83	.009* AN > BN‡
New direction in education or new job	2.14 (1.21)	1.97 (1.13)	1.90 (1.24)	*H* = 1.83	.40
Medication	2.16 (1.15)	1.78 (1.10)	1.96 (1.08)	*H* = 5.41	.07
Specific aspect of treatment	2.16 (1.26)	1.73 (1.13)	1.92 (1.23)	*H* = 5.35	.07
Changing another important aspect of life	1.88 (1.07)	1.96 (1.14)	2.22 (1.12)	*H* = 2.83	.24
Support groups/organisations	**1.75 (0.94)**	**1.58 (0.98)**	**2.28 (1.22)**	***H* = 10.8**	**.005*** **BED > BN‡** **BED > AN‡**
New relationship	1.70 (1.06)	1.73 (1.08)	1.83 (1.23)	*H* = .24	.89
Having a child	1.24 (0.72)	1.32 (0.86)	1.45 (0.99)	*H* = 2.14	.34

Note. * = Statistically significant at level $p < .01$. ** = Statistically significant at level $p < .05$.
†ANOVA test (*F*) for normal distribution or Kruskal-Wallis test (*H*). ‡ Determined using post-hoc test.

4.3.5.3 Multivariate Analyses of Factors Associated with ED Diagnostic Group

Multinomial logistic regression modelling was conducted to establish the relative contribution of potential causal and recovery factors in predicting ED diagnosis, to further examine the extent and magnitude of any diagnostic variations found through the univariate analyses.

Model of causal factors: Firstly, the potential causal factors found to have a significance level of ≤ .10 through the univariate analyses were incorporated. A total of seven variables therefore were entered into the model: “it made me feel a sense of control in my life”, “I felt pressure to be thin”, “certain aspects of my personality made me more susceptible”, “I was bullied or teased about my weight or appearance”, “certain issues that happened to me as a child”, “it is a biological or genetic illness” and “I was teased or bullied about other things”. Results are presented in Table 9. The model explained 29.7% of the variance in the ED diagnostic group ($\chi^2(14) = 67.6$, $p < .001$). “It made me feel a sense of control in my life”, “I was bullied or teased about my weight or appearance” and “it is a biological or genetic illness" were statistically significant contributors remaining in the model in predicting the ED diagnostic group.

In the second step, age, age of onset of first ED symptoms, and duration of ED were added, to check for any possible confounding impact of these variables. Thus, a total of ten variables were entered into the model. The variance explained increased to 37.7% ($\chi^2(20) = 86.7$, $p < .001$). The three factors from the first step remained statistically significant. Participants who endorsed “it made me feel a sense of control in my life” were 25.0 times more likely to be in the AN group than the BED group, 8.3 times more likely to be in the BN group than the BED group, and 2.9 times more likely to be in the AN group than the BN group. Participants who endorsed “I was bullied or teased about my weight or appearance” were 3.63 times more likely to be in the BED group than the AN group. Participants who endorsed “it is a biological or genetic illness” were 2.44 times more likely to be in the AN group than the BN group. As duration of ED increased, the odds of being in the BED group rather than the AN and the BN group increased. As age of onset of first ED symptoms increased, the odds of being in the BN group rather than the AN group increased.

Table 9

Multinomial regression modelling of the contribution of potential causal factors in predicting the likelihood of ED diagnostic group (AN, BN or BED)

	Step 1		Step 2					
Variable[†]	χ^2	*p*	χ^2	*p*	B	OR	*p*	95% CI
It made me feel a sense of control in my life	31.1	< .001*	29.5	< .001*				
- AN x BN					-1.01	0.35	.04**	0.13; 0.96
- AN x BED					-3.22	0.04	< .001*	0.01; 0.14
- BN x BED					-2.16	0.12	< .001*	0.04; 0.37
I felt pressure to be thin	2.78	.25	3.05	.22				
Certain aspects of my personality made me more susceptible	0.29	.86	4.51	.11				
I was bullied or teased about my weight or appearance	12.2	.002*	6.02	.05**				
- AN x BN					0.63	1.88	.08	0.93; 3.80
- AN x BED					1.29	3.63	.04**	1.04; 12.7
- BN x BED					0.66	1.93	.31	0.54; 6.90
Certain issues that happened to me as a child	3.13	.21	2.72	.26				
It is a biological or genetic illness	7.29	.03**	7.78	.02**				
- AN x BN					-0.90	0.41	.01**	0.20; 0.82
- AN x BED					-0.99	0.37	.09	0.12; 1.19
- BN x BED					-0.10	0.91	.88	0.28; 3.00
I was teased or bullied about other things	2.33	.31	0.82	.67				
Age			2.46	.30				
Age of onset of first ED symptoms			6.23	.04**				
- AN x BN					0.09	1.09	.04**	1.01; 1.19
- AN x BED					0.13	1.14	.07	0.99; 1.30
- BN x BED					0.04	1.04	.57	0.92; 1.18
Duration of ED[‡]			17.1	< .001*				
- AN x BN					0.04	1.04	.12	0.99; 1.10
- AN x BED					0.17	1.18	.001*	1.02; 1.25
- BN x BED					0.12	1.13	.02**	0.80; 0.98
Nagelkerke R^2	.297		.377					
Overall model χ^2	67.6, *df*=14, *p* < .001*		86.7, *df*=20, *p* < .001*					

Note. * = Statistically significant at level *p* < .01. ** = Statistically significant at level *p* < .05. [†]Regression coefficient, odds ratio (OR), 95% confidence interval (CI) and *p*-value for each diagnostic comparison shown for statistically significant variables in step 2. [‡]Missing values calculated using ‘age’ – ‘age of onset’.

Model of recovery factors: Firstly, potential recovery factors found to have a significance level of ≤ .10 through the univariate analyses were incorporated. Therefore, eight variables were entered into the model: “family/partner/friends support”, “tackling issues around food and body image”, “increase in self-esteem”, “good relationship with treatment team”, “family/partner involvement in treatment”, “medication”, “specific aspect of treatment” and “support groups/organisations”. Results are presented in Table 10. The model explained 16.5% of the variance in the ED diagnostic group ($\chi^2(16) = 30.1$, $p = .02$). The potential recovery factor “increase in self-esteem” was the only statistically significant contributor to ED diagnostic group.

In the second step, age, age of onset of first ED symptoms, and duration of ED were added, thus a total of 11 variables were entered into the model. Results are presented in Table 10. The variance explained increased to 28.7% ($\chi^2(22) = 54.2$, $p < .001$). The potential recovery factor “increase in self-esteem” remained a statistically significant contributor to the ED diagnostic group. Participants who endorsed “increase in self-esteem” were 2.23 times more likely to be in the BN group than AN group. Furthermore, as age of onset increased, the odds of being in the BN group rather than the AN group increased. As duration of ED increased, the odds of being in the BED group rather than AN group increased.

Table 10

Multinomial regression modelling of the contribution of potential recovery factors in predicting the likelihood of ED diagnostic group (AN, BN or BED)

	Step 1		Step 2					
Variable[†]	χ^2	*p*	χ^2	*p*	B	OR	*p*	95% CI
Family/partner/friends support	0.76	.69	1.95	.38				
Tackling issues around food and body image	2.73	.26	1.35	.51				
Increase in self-esteem	6.78	.03**	6.13	.05**				
- AN x BN					0.80	2.23	.03**	1.08; 4.62
- AN x BED					-0.39	0.68	.52	0.21; 2.21
- BN x BED					-1.19	0.31	.06	0.09; 1.07
Good relationship with treatment team	2.27	.32	0.12	.94				
Family/partner involvement in treatment	3.76	.15	4.23	.12				
Medication	4.17	.13	3.81	.15				
Specific aspect of treatment	3.43	.18	4.19	.12				
Support groups/organisations	3.06	.22	0.62	.73				
Age			0.90	.64				
Age of onset of first ED			6.67	.04**				
- AN x BN					0.08	1.08	.04**	1.01; 1.17
- AN x BED					-0.01	0.99	.84	0.88; 1.11
- BN x BED					-0.09	0.91	.12	0.81; 1.03
Duration of ED[a]			6.67	.04**				
- AN x BN					0.03	1.03	.27	0.98; 1.08
- AN x BED					0.08	1.08	.02**	1.01; 1.16
- BN x BED					0.05	1.05	.15	0.98; 1.13
Nagelkerke R^2	.165				.287			
Overall model χ^2	30.1, *df*=16, *p* = .02**				54.2, *df*=22, *p* < .001*			

Note. * = Statistically significant at level $p < .01$. ** = Statistically significant at level $p < .05$. [†]Regression coefficient, odds ratio (OR), 95% confidence interval (CI) and *p*-value for each diagnostic comparison only shown for statistically significant variables. [‡]Missing values calculated using ‘age’ – ‘age of onset’.

4.3.6 Comparison of Causal and Recovery Factors Between Recovered and Non-Recovered Categories

4.3.6.1 Potential Causal Factors

Exploratory analyses were conducted to examine any differences between participants in the recovered and non-recovered categories, in their endorsement of potential causal factors. Independent t-tests and Mann-Whitney U tests (dependant on distribution) were conducted (see Table 11). As previously explained in section 4.2.5, means and standard deviations are presented in the table, however the statistics reported for the Mann-Whitney U tests were calculated using mean ranks (detailed in the text for the statistically significant results).

The potential causal factor “it helped me cope when feeling stress or other negative emotions” was endorsed to a greater extent by participants in the non-recovered category than the participants in the recovered category (mean rank of 134 compared with 116). “I was having difficulty coping with major life changes” was also endorsed to a greater extent by participants in the non-recovered category than participants in the recovered category (mean rank of 189 compared with 168).

Table 11

Comparison of participants' endorsement of each potential causal factor, for those in the recovered and non-recovered categories

Causal Factor	**Recovered** **M (SD)** **(n = 195)**	**Non-Recovered** **M (SD)** **(n = 169)**	**U or $t^{\dagger}$**	**p**
I had low self-esteem	3.49 (0.66)	3.50 (0.78)	U = 15175	.36
It helped me cope when feeling stress or other negative emotions	3.34 (0.98)	3.68 (0.55)	U = 6595	.02**
I felt pressure to succeed and be perfect	3.29 (1.06)	3.40 (0.91)	U = 7283	.57
It made me feel a sense of control in my life	3.32 (1.03)	3.41 (0.97)	U = 7372	.52
I felt pressure to be thin	3.21 (0.92)	3.16 (0.97)	U = 15598	.70
Certain aspects of my personality made me more susceptible	3.09 (0.95)	3.13 (0.91)	U = 7439	.81
I was having difficulty coping with major life changes	2.81 (1.10)	3.05 (1.00)	U = 13720	.04**
There was no-one to share my innermost thoughts and feelings with	2.69 (1.09)	2.83 (1.06)	U = 14809	.23
A reaction to traumatic life event(s) or experience(s)	2.54 (1.24)	2.68 (1.20)	t = .89	.37
I was bullied or teased about my weight or appearance	2.34 (1.09)	2.45 (1.09)	t = .99	.33
There was conflict with key people in my life	2.50 (1.20)	2.58 (1.17)	t = .62	.54
Certain issues that happened to me as a child	2.49 (1.21)	2.56 (1.20)	t = .54	.59
It is a biological or genetic illness	2.19 (1.04)	2.35 (1.10)	t = 1.40	.16
I was teased or bullied about other things	2.15 (1.05)	2.28 (1.09)	t = 1.14	.26
I don't know why I developed an ED	1.72 (1.06)	1.97 (1.17)	U = 7371	.08

Note. * = Statistically significant at level $p < .01$. ** = Statistically significant at level $p < .05$. †T-test (t) for normal distribution or Mann-Whitney U test (U)

4.3.6.2 Potential Recovery Factors

Exploratory analyses were conducted to examine any differences between participants in the recovered and non-recovered categories, in their endorsement of potential recovery factors. As also noted earlier, 28.4% (*n* = 23) of the participants who reported they *still have a significant ED* did not respond to this section of the survey. Independent t-tests and Mann-Whitney U tests (dependant on distribution) were conducted (see Table 12). As previously explained in section 4.2.5, means and standard deviations are presented in the table, however the statistics reported for the Mann-Whitney U tests were calculated using mean ranks (detailed in the text for the statistically significant results).

The potential recovery factor “own motivation” was endorsed to a greater extent by participants in the recovered category than participants in the non-recovered category (mean rank of 181 compared to 143), and “tackling underlying causes” was endorsed to a greater extent by participants in recovered category than the non-recovered category, (mean rank of 116 compared to 98). The factors “being treated as an individual” and “increase in self-esteem” were also endorsed to a greater extent by participants in the recovered category than participants in the non-recovered category.

Table 12

Comparison of participants' endorsement of each potential recovery factor, for those in the recovered and non-recovered categories

Recovery Factor	**Recovered *M* (*SD*) (*n* = 195)**	**Non-Recovered *M* (*SD*) (*n* = 169)**	***U or t*** †	***p***
Own motivation	3.56 (0.71)	1.97 (1.17)	*U* = 10186	<.001*
Tackling underlying causes	3.07 (1.07)	2.73 (1.17)	*U* = 4749	.03**
Family/partner/friends support	2.81 (1.10)	2.78 (1.17)	*U* = 5897	.99
Tackling issues around food and body image	2.91 (1.06)	2.65 (1.09)	*U* = 4934	.07
Able to express and cope with negative emotions in alternative ways	2.81 (1.09)	2.61 (1.14)	*U* = 5128	.19
Having some control over my treatment and recovery	2.87 (1.18)	2.63 (1.18)	*U* = 4981	.10
Being treated as an individual	2.87 (1.22)	2.43 (1.34)	*t* =-2.46	.02**
Increase in self-esteem	2.77 (1.04)	2.22 (1.10)	*t* = -3.75	<.001*
Good relationship with treatment team	2.49 (1.25)	2.47 (1.27)	*t* = -.18	.86
Family/partner involvement in treatment	2.38 (1.19)	2.29 (1.16)	*t* = -.65	.51
New direction in education or new job	2.07 (1.22)	2.06 (1.15)	*U* = 12876	.98
Medication	1.97 (1.14)	2.09 (1.13)	*U* = 5504	.41
Specific aspect of treatment	2.02 (1.25)	1.97 (1.20)	*U* = 5046	.68
Changing another important aspect of life	1.97 (1.14)	1.87 (1.03)	*U* = 12132	.58
Support groups/organisations	1.74 (1.02)	1.75 (0.97)	*U* = 12608	.80
New relationship	1.78 (1.12)	1.62 (1.01)	*U* = 11875	.21
Having a child	1.34 (0.86)	1.20 (0.66)	*U* = 11917	.22

Note. * = Statistically significant at level $p < .01$. ** = Statistically significant at level $p < .05$. †T-test (*t*) for normal distribution or Mann-Whitney U test (*U*).

4.3.6.3 Multivariate Analyses of Factors Associated with Recovery Status

Binary logistic regression was carried out to determine the relative contribution of each potential causal and recovery factor in predicting recovery status, to further explore any variations found between the recovered and non-recovered categories in the univariate analyses.

Model of causal factors: Firstly, the model incorporated all of the potential causal factors that were found to have a significance level of $\leq .10$ through the univariate analyses; the two included variables were "it helped me cope when feeling stress or other negative emotions" and "I was having difficulty coping with major life changes". Results are presented in Table 13. The model explained 10.1% of the variance in recovery status ($\chi^2(2) = 18.4$, $p < .001$). The only candidate causal variable that was a statistically significant contributor to the likelihood of being in the recovered category was "it helped me cope when feeling stress or other negative emotions".

The variables of age, age of onset of first ED symptoms, and duration of ED were then added to the model in step two to check for any possible confounding impact of these variables on recovery status. The variance explained by the model increased to 20.4% ($\chi^2(5) = 38.7$, $p < .001$). "It helped me cope when feeling stress or other negative emotions" remained a statistically significant contributor to recovery status; participants were 8.49 times more likely to be in the recovered category if they did not endorse the factor. As age increased, the likelihood of being in the recovered category increased. As age of onset and duration of ED increased, the likelihood of being in the recovered category decreased.

Table 13

Binary logistic regression modelling the contribution of potential causal factors in the prediction of ‘recovered’ status

Variable[†]	**Step 1**				**Step 2**			
	B	*p*	OR	95% CI	*B*	*p*	OR	95% CI
It helped me cope when feeling stress or other negative emotions	2.26	.003*	9.55	2.16; 42.28	2.14	.009*	8.49	1.72; 41.91
I was having difficulty coping with major life changes	.45	.14			0.48	.13		
Age					0.11	.001*	1.11	1.05; 1.19
Age of onset of first ED					-0.14	.002*	.87	.80; .95
Duration of ED[a]					-.010	.004*	.90	.84; .97
Nagelkerke R^2	.101				.204			
χ^2	18.4, *df*=2, *p* <.001*				38.7, *df*=5, *p* <.001*			

Note. * = Statistically significant at level $p < .01$. ** = Statistically significant at level $p < .05$. [a]Missing values calculated using ‘age’ – ‘age of onset’. [†]Odds ratio (OR) and 95% confidence interval (CI) shown only for statistically significant variables.

Model of recovery factors: All of the potential recovery factors that had been found to have a significance level of ≤ .10 through the univariate analysis were added in the first step; a total of six variables. The variables entered were: “own motivation”, “tackling underlying causes”, “tackling issues around food and body image”, “having some control over my treatment and recovery”, “being treated as an individual” and “increase in self-esteem”. Results are presented in Table 14. The model explained 15.5% of the variance in recovery status ($\chi^2(6) = 24.7$, $p < .001$). There were two factors that were statistically significant contributors to the likelihood of being in the recovered category: “own motivation” and “increase in self-esteem”.

As with the previous models, age, age of onset of first ED symptoms, and duration of ED were then added in step two to check for any possible confounding impact of these variables. The variance explained by the model increased to 26.3% ($\chi^2(9) = 43.9$, $p < .001$). The potential recovery factor of “own motivation” remained statistically significant, with participants 4.55 times more likely to be in the recovered category if they endorsed the factor. The potential recovery factor of “increase in self-esteem” also remained statistically significant, with participants 1.96 times more likely to be in the recovered category if they endorsed the factor. As age increased, the likelihood of being in the recovered category increased. As age of onset and duration of ED increased, the likelihood of being in the recovered category decreased.

Table 14

Binary logistic regression modelling the contribution of potential recovery factors in the prediction of 'recovered' status

	Step 1				**Step 2**			
Variable[†]	*B*	*p*	OR	95% CI	*B*	*p*	OR	95% CI
Own motivation	-1.42	.008*	.24	.09; .69	-1.50	.007*	.22	.07; .67
Tackling underlying causes	-.33	.35			-.42	.27		
Tackling issues around food and body image	-.36	.30			-.45	.21		
Having some control over my treatment and recovery	.58	.16			.51	.24		
Being treated as an individual	-.54	.16			-.37	.37		
Increase in self-esteem	-.64	.05**	.53	.28; 1.00	-.68	.05**	.51	.26; .99
Age					.10	.004*	1.10	1.03; 1.17
Age of onset of first ED					-.13	.003*	.88	.81; .96
Duration of ED[a]					-.11	.002*	.90	.84; .96
Nagelkerke R^2	.155				.263			
χ^2	24.7, *d*f=6, *p* <.001*				43.9, *d*f=9, *p* <.001*			

Note. * = Statistically significant at level *p* < .01. ** = Statistically significant at level *p* < .05. [a]Missing values calculated using 'age' – 'age of onset'. [†]Odds ratio (OR) and 95% confidence interval (CI) shown only for statistically significant variables.

4.3.7 Summary of Key Results

Consistent with the initial hypothesis about causal factors of an ED, the top four most frequently endorsed potential causal factors were: “I had low self-esteem”, “it helped me cope when feeling stress or other negative emotions”, “I felt pressure to succeed and be perfect” and “it made me feel a sense of control in my life”. Self-esteem featured as both a prominent causal and recovery factor. In addition to “I had low self-esteem” being the most frequently endorsed causal factor, the potential recovery factor “increase in self-esteem” was a significant predictor of recovery status (with participants who endorsed the factor being more likely to be in the recovered category). In addition to being a highly endorsed causal factor, “it helped me cope when feeling stress or other negative emotions” was also the strongest potential causal factor in predicting recovery status; participants who endorsed the factor as a cause were more likely to be in the non-recovered category.

The factor “I felt pressure to be thin” was also endorsed as a causal factor by the majority of participants. Contrary to the hypothesis though, the potential causal factors “a reaction to traumatic life event(s) or experience(s)”, “I was bullied or teased about my weight or appearance” and “I was teased or bullied about other things” were lower in the rankings than expected. Furthermore, the hypothesis that participants with BN would be more likely to endorse experiencing trauma as a causal factor than AN and BED was not supported.

There were some diagnostic differences found. The strongest causal factor in predicting diagnostic group was “it made me feel a sense of control in my life”. Participants with AN were significantly more likely to endorse the factor than participants with both BN and BED, and participants with BN were significantly more likely to endorse the factor than participants with BED. In addition to the item about control, BED was found to differ from AN and BN in a number of other ways. Firstly, participants with BED were more likely to endorse “I was bullied or teased about my weight or appearance” as a causal factor than participants with AN. Unlike AN and BN, they were also more likely to report that they did not know why they developed their ED. In relation to treatment, participants with BED were more likely than participants with AN and BN to endorse “tackling issues around food and body image” and “support groups/organisations” as assisting recovery. It was hypothesised that participants with BN would also be more likely than participants with AN to endorse the two aforementioned recovery factors but this was not found to be the case.

Across all diagnostic groups, the most frequently endorsed potential recovery factors were: “own motivation”, tackling underlying causes”, family/partner/friends support”, and “tackling issues around food and body image”. Only two of these factors (tackling underlying causes and having support) were consistent with the hypothesis. The other factors hypothesised to be highly endorsed (“good relationship with treatment team” and “being treated as an individual”) were actually endorsed by just over half of the participants. The potential recovery factor “being treated as an individual” was however more frequently endorsed by participants in the recovered category than the non-recovered category.

In addition to “being treated as an individual”, three other potential recovery factors were endorsed significantly more frequently by participants in the recovered category than the non-recovered category: “own motivation”, “tackling underlying causes” and “increase in self-esteem”. The strongest factor in predicting recovery status was “own motivation”; participants who endorsed this factor as assisting in the recovery process were more likely to be in the recovered category than the non-recovered category.

4.4 Discussion

The aim of this quantitative study was to improve understanding of the factors women with lived experience of an ED perceive to be important in causing their disorder and that contributed to improvements and recovery. All 14 of the potential causal factors were endorsed by at least 43% of participants, showing that women with lived experience perceived a range of different factors to be involved in the onset of an ED. As hypothesised, over 80% of participants endorsed having low self-esteem, using the ED to help cope with negative emotions, and feeling pressure to be perfect as contributing to the onset of their ED, whether the ED was AN, BN or BED. While several causal and recovery factors were common across participants regardless of diagnosis or recovery status, there were also some interesting differences detected.

4.4.1 Self-Esteem

Low self-esteem was the most frequently endorsed cause of an ED, supporting previous findings that low self-esteem is associated with AN (Brockmeyer et al., 2013), BN (Daley et al., 2008) and BED (Dunkley & Grilo, 2007). The present cross-sectional study, however, found only low correlations between low self-esteem and other potential causal factors, inconsistent with research that suggested associations or interactions between self-esteem and other factors such as perfectionism (Vohs et al., 2001), stress, and maladaptive coping (Fryer et al., 1997). Self-esteem appears to be robustly related to both onset and recovery from an ED. Consistent with the findings for recovery in the present data, other studies have found that low self-esteem predicts a poor treatment outcome (Wade et al., 2011) and higher self-esteem a more positive outcome (Vall & Wade, 2015). The large magnitude positive correlation between endorsement of an increase in self-esteem and being able to cope with negative emotions in alternative ways as recovery factors supports Fryer et al. (1997)'s assertion that teaching healthy ways of coping in treatment may in fact improve self-esteem. Feeling competent at coping may also help increase self-efficacy and thus self-esteem.

4.4.2 Coping with Emotions

Findings from the present study are consistent with other research which has found that coping strategies play an important role in EDs, encompassing both onset and recovery. In the current study, the perception that the ED was helpful in coping with stress and with negative emotions was the second most frequently endorsed causal factor. This supports the conclusions from other studies that have found those with an ED (AN, BN and BED) often have inadequate coping mechanisms (Marchiol et al., 2020) and difficulties in emotion regulation (Brockmeyer et al., 2014).

Interestingly, perceiving the ED as helping to cope also suggests that participants considered their ED to be serving a positive function. Rossotto et al. (1996) found that participants who were classed as non-recovered spoke of positive aspects of their disorder, including using it as an escape from feelings, whereas recovered participants did not. Given that the strongest potential causal factor in predicting recovery status in the present study was the ED being viewed as helping to cope with stress and other negative emotions (with high endorsement increasing the likelihood of being in the non-recovered category), viewing the ED as serving an affect regulation function could represent a substantial barrier to recovery. It may also suggest that participants in the non-recovered category were experiencing ambivalence towards their ED; feelings which have been determined to be a maintenance factor in AN (Williams & Reid, 2010). Findings therefore suggest changing the perspective that EDs serve a positive function is likely to remove the ambivalence and be an essential part of recovery.

4.4.3 Perfectionism and the Thin Ideal

Feeling pressure to succeed and be perfect, and feeling pressure to be thin, were both perceived as causes of the ED by the majority of participants. This finding is consistent with a considerable body of existing research that has found clinical perfectionism to be both a risk and maintenance factor for EDs (Bardone-Cone et al., 2007; Egan et al., 2011). Media exposure has been linked to internalisation of a thin-ideal body type and disturbed eating behaviours and attitudes (Grabe et al., 2008), suggesting media portrayals of thin as the ideal figure may be perceived as pressure to look that way by some individuals. Bardone-Cone et al. (2007) proposed that perfectionism can lead to an ED due to sensitivity to social expectations, a need to receive validation from others to attain a high social status, and viewing low body weight as a source of positive feedback. Thompson et al. (2013) suggested that the link between perfectionism and ED symptoms is exacerbated by internalisation of media attitudes towards appearance.

4.4.4 Trauma

In this study, the participants' perception that their ED was a reaction to some form of trauma was endorsed to a lesser extent than expected. A link between EDs and sexual trauma is well documented in the literature (e.g. Fairburn et al., 1998; Forman-Hoffman et al., 2012; Waller, 1998). Brewerton (2007) concluded from a review that any experience that has the potential to produce post-traumatic stress or anxiety is a risk factor for an ED. It could be the case that not all participants in the present study perceived 'trauma' to refer to the same experiences, as Rorty et al. (1995) found participants and researchers varied in what they viewed as abuse. Furthermore, Ball and Lee (2000) determined from their review that stressful life events may contribute to the development of disordered eating in many cases but are not a necessity. With around half of participants in the present study perceiving their ED to be a reaction to a traumatic event, this proportion was only slightly lower than that reported by Tagay et al. (2010).

The association between the causal factors of experiencing trauma and having conflict with key people in life raises the possibility that trauma involving or impacting upon close relationships may be more strongly linked to developing an ED than other forms of trauma or stress. Other research has found major life stressors reported by participants with AN and BN were most commonly categorised as involving close relationships e.g. parental divorce or sexual abuse by a close family member (Schmidt et al., 1997). Alternatively, it could be that trauma impacts upon a person's ability to maintain an agreeable relationship. As a cross-sectional study, it was not possible to address causality regarding the reason for the correlation found here.

The hypothesis that a greater proportion of participants with BN would endorse experiencing trauma as a reason for the onset of their ED was not supported. While this lack of a diagnostic difference contradicts previous findings (e.g. Fairburn et al., 1998; Speranza et al., 2003; Waller, 1991, 1993), the present findings are consistent with a small number of studies reporting similar levels of trauma in both AN and BN (Schmidt et al., 1997; Tagay et al., 2010). There have also been contradictory findings in relation to specific types of abuse, with some research suggesting that CSA is associated with the development of binge eating, particularly when committed by a family member (Waller, 1992b). Other findings suggested BN symptoms were more likely when extrafamilial abuse occurred over the age of 12 (Beckman & Burns, 1990). These inconsistencies demonstrate that diagnostic variations may be more complex and different types of trauma may influence different symptoms rather than simply the occurrence of trauma alone.

4.4.5 Bullying

Similar to the findings about trauma, the perception that being bullied or teased by peers about appearance or other things was less endorsed than hypothesised. A history of having been bullied has previously been strongly associated with having an ED, particularly being bullied about appearance (Lie et al., 2019). Although lower than expected, the frequency of reporting in the present findings, however, were comparable to those of Sweetingham and Waller (2008), with around half of participants perceiving being bullied as a cause of their ED. In the survey used for the present study, there were two separate items relating to bullying as a causal factor; incidents focusing on weight or appearance, and incidents with other foci. Endorsement may have been higher had only one item been used incorporating all forms of bullying.

The present study did find that participants with BN and BED were more likely than participants with AN to endorse being bullied or teased about their weight or appearance as a causal factor, suggesting there may be diagnostic differences in social interactions and experiences. Being bullied about appearance has been associated with elevated body dissatisfaction and lowered self-esteem (Eisenberg et al., 2003) Previous studies have reported a high prevalence of fat-shaming (e.g. Chou et al., 2014; Hussin et al., 2011), demonstrating the psychological impact negative experiences can have and the different types of stigma women with BED may have experienced in their lives. Although being overweight is not a criteria of BED, most studies report higher current BMIs in those with BED (e.g. Grilo et al., 2009; Grucza et al., 2007), making them more vulnerable to fat shaming. Childhood weights were not collected in this study so it is unknown if overweight status as a child might have been a focus of bullying.

4.4.6 Further Diagnostic Differences

BED appeared to differ from AN and BN in a number of ways. Participants with BED were more likely than participants with BN and AN to respond that they did not know why they developed an ED. Interestingly, fewer than a third of participants overall stated that they did not know why they developed an ED, indicating that the majority felt a degree of certainty over the reasons for their ED. Participants with BED were also less likely to have experienced treatment and so it is possible that they had not discussed or reflected on the underlying causes of their ED (as typically happens in an assessment or early treatment sessions) to be able to arrive at their own formulation.

Given previous research has suggested that BN and BED are more similar to each other than to AN, it was expected that perceived helpful factors in treatment would be more closely aligned for BN and BED than AN. Jordan et al. (2014) found both BED and BN with non-purging compensatory behaviours shared features of higher weight and/or BMI, and lower specialist ED treatment experiences. A similarity in body weight may explain why, as previously discussed, participants with BN as well as BED were more likely than AN to perceive being bullied about their weight to be a cause. Contrary to the hypothesis, the similarity between participants with BN and BED in the present study, however, did not extend to their views on focusing on body image in treatment or the usefulness of support groups. Participants with BED were more likely than participants with either AN or BN to endorse that tackling issues around food and body image was a recovery factor. This could allude to a more complex relationship with food, or greater body dissatisfaction in women with BED (Fassino et al., 2004), whether as a cause, effect, or presence. High body dissatisfaction in women with BED may also be linked to experiences of bullying, in particular fat-shaming, as discussed in the previous section.

Support groups and organisations were also more likely to be endorsed as an important factor for recovery by participants with BED than both AN and BN. The reason for this is not clear. However, Hertz et al. (2012) found that participants who attended Overeaters Anonymous used food to overcome loneliness, and therefore benefited from the social environment and positive attachments they were able to make. The diagnostic difference in endorsement of support groups may also reflect the fact that a greater number of women with BED did not have specific ED treatment, implying they were more likely to attend community support groups in place of formal ED treatment. This was confirmed in a review by Mitchison et al. (2017) who concluded that people with BED are less likely to receive mental health treatment and instead are much more likely to receive a referral for dietary or exercise advice. As noted in the literature review here, research into treatment experiences for BED, particularly seeking the views of women with lived experience, is extremely limited, but one study did find that group therapy was rated as the most helpful treatment (more than individual therapy or a dietician) (Higgins Neyland & Bardone-Cone, 2019).

Although BN did not differ from AN in regards to the helpfulness of support groups and tackling body image (contrary to the hypothesis), there were several factors that did differentiate AN and BN. Firstly, the older age of onset in BN compared to AN is a well-established finding (Nagl et al., 2016; Steinhausen & Jensen, 2015). Outside of treatment, support from family, friends and/or a partner was one of the most frequent factors perceived to assist in recovery, however it appeared to be less influential in BN. This could reflect the older age of onset for BN compared with AN.

The relative strength of endorsement of psychological factors in AN, such as personality and control, compared to appearance-related factors, such as being bullied about appearance or tackling issues around body image, might indicate that, for women in the present sample at least, AN is perceived to be more about psychological traits and perceived benefits of the ED than about physical appearance. This perception was echoed in the voices of clients with AN in previous qualitative research (e.g. Rance et al., 2017b). Women with AN were also more likely to endorse having a good relationship with the treatment team and having their family or partner involved in treatment as recovery factors. The difference in perceptions around factors within treatment may suggest that feeling connected to someone during treatment is of greater importance for AN. It may also reflect that more women with AN than BN and BED have had first-hand experience of these factors to be able to evaluate their effectiveness. For instance, a greater percentage of participants with AN reported experiencing family-based therapy than both BN and BED.

The strongest predictor of diagnostic group was endorsement of the causal factor “it made me feel a sense of control in my life”, implying that the perceptions of control play a key role in the differentiation between ED diagnoses. Consistent with the hypothesis, both AN and BN were more likely than BED to be used to gain a sense of control. This finding suggests that women with AN and BN may feel they have low levels of internal control (Tiggemann & Raven, 1998) and therefore use their ED to try and address this feeling. Furthermore, participants with AN were significantly more likely to endorse feeling a sense of control than participants than BN, implying that perception of control may be of particular relevance in AN. This finding is consistent with the theoretical and research literature proposing that the concept of control is a key feature in AN (Surgenor et al., 2002). Surgenor et al. (2003), for example, has suggested that different aspects of control contribute to different clinical behaviours within AN. For those with BN, the influence of control may feature more heavily in the subgroups who maintain a greater level of restriction.

4.4.7 Recovery Factors within Treatment

In relation to helpful factors within treatment, having a good relationship with the treatment team and being treated as an individual was not endorsed as frequently as expected. In their meta-analysis, Graves et al. (2017) determined that a strong therapeutic alliance was associated with a positive outcome in ED treatment, however, additional factors such as age and type of treatment may have an impact on how influential the role of alliance is. There is some debate as to the importance of the therapeutic alliance in psychological treatments, with some research suggesting too much emphasis may be placed on the significance of the relationship (Brown et al., 2013; Carter et al., 2015). A good therapeutic alliance may reduce premature dropout from treatment rather than be a factor in improving treatment efficacy itself (Jordan et al., 2017). It is possible that factors relating to treatment were endorsed to a lesser extent due to the participants who had not received any specialist treatment and therefore had no experience with a treatment team to refer to when responding. The finding here that participants in the recovered category were more likely to perceive being treated as an individual as beneficial for recovery indicates it is an important factor in treatment, which has been commonly identified in qualitative studies (e.g. Pettersen & Rosenvinge, 2002; Rance et al., 2017b) but less explored quantitatively.

Tackling underlying causes was one of the most frequently endorsed recovery factors, suggesting it is perceived as an important aspect across all EDs. Interestingly, there did not appear to be a relationship between perceiving self-esteem, coping and control as causes, and addressing or considering these same factors in recovery. This would suggest that focusing on the underlying causes, while perceived as beneficial by the client, may not be the most effective course of action for the therapist. Focusing on maintenance factors may be more fruitful in making progress towards recovery. In support of this, Fairburn et al. (2009) found that CBT-E, which targets the key maintenance factors of perfectionism, low self-esteem, mood tolerance and interpersonal problems, was more effective than CBT for individuals in which those specific maintaining factors were present. CBT-E was however less effective than CBT for individuals who were not experiencing the maintenance factors. These findings provide further support that tailoring treatment for the individual may improve treatment efficacy, and suggests that increases in self-esteem and the use of alternative coping strategies may actually be beneficial due to addressing maintenance rather than causal factors. While data on maintenance factors were not explicitly collected through the present survey, participant perceptions on maintenance factors were explored in the qualitative study and the findings are considered alongside the quantitative data in the final chapter.

4.4.8 Self-Motivation

Schmidt et al. (2014), in the development of MANTRA, also focused upon targeting perfectionism and intolerance of negative emotions to interrupt maintenance factors in AN; factors which were identified as important in the present study. MANTRA also included motivational interviewing as a means to increase self-motivation in participants. Findings from the present study suggested self-motivation is important in recovery from an ED, as it was the most frequently endorsed recovery factor and the strongest predictor of recovery status. Although some other treatments already include motivational elements (e.g. CBT), these findings highlight the importance of incorporating techniques to increase self-motivation to improve treatment efficacy. Research into the impact of focusing on enhancing self-motivation in treatment however has been inconclusive (Knowles et al., 2013).

4.5 Limitations

There are several limitations pertaining to the present quantitative study, which are outlined here. Firstly, the overall sample size was relatively modest, with low ethnic diversity in the sample, which restricted the ability to generalise the findings to the wider population and to robustly test hypotheses. Despite continued efforts, including reposting across the online platforms that had generated the best response rates, revisiting physical advertising locations to redisplay posters and extending the recruitment period, the rate of increase was gradual and numbers were lower than expected. The participants in this thesis were also restricted to New Zealand women aged over 16 years who volunteered to participate. The sample was appropriate to explore the research questions but limited the generalisability of the findings beyond the demographics of the sample. Even with the lengthy recruitment period, multiple channels of advertisement used and the exploratory nature of the study, limitations regarding the sample size must be acknowledged.

The small sample size was also relevant when participants were separated into diagnostic groups, limiting the statistical power of some of the comparative analyses. In addition, the sample was unevenly distributed across each diagnostic group. As explained in section 4.2.2.2, despite additional focused advertising, there was a lower response rate from women with BED than the other diagnostic subtypes. The diagnostic differences identified through the statistical analyses therefore need to be considered with a high level of caution. The aim of this research, however, was to explore the participants' perceptions rather than to generalise the results. Additionally, the recovery status and diagnostic group comparisons were solely conducted separately, rather than also combining the groupings (such as comparing recovered participants with BN with non-recovered participants with AN). The small sample size limited the ability to break the participants down into groups at this level. This was not considered a significant limitation as this additional depth of analysis would not have contributed to answering the research questions.

There are several limitations based on the survey measure used. The items used to collect data on causal and recovery factors were a list of items based on factors identified through the literature review, that were mainly developed for the purpose of this study, not a validated psychometric scale. As similar research has not been completed before, an appropriate existing scale could not be identified. This limitation is one reason why the triangulation from the qualitative study is important. The survey design also restricted data collection and analysis to the predefined factors featured in the questions and the multiple choice options provided, meaning that every potential causal and recovery factor could not be considered. Context and reasons for participant responses could not be collected. The survey was of self-report design, which relied on the participants to accurately recall their motivations for behaviour that may have occurred at some time in the past. The data may therefore be subject to recall bias. The diagnostic groups were determined based on self-reported data rather than a structured clinical assessment. This was appropriate to allow participants to maintain anonymity and has a number of strengths (discussed in the next section below), but could mean some participants did not meet the full criteria for the disorder they reported. By taking part in the research, however, it demonstrated that they felt their relationship with food adversely impacted on their health or life functioning. Their opinions were therefore still considered to be of importance.

As the study was cross-sectional, causality could not be established and only associations could be inferred. During analysis of the data, some corrections were not made for multiple analyses as the research was exploratory. Despite this limitation, the results were, in most cases, consistent with existing literature. The survey responses also represent the participants' views at one moment in time. It is possible that opinions on factors that are helpful for recovery could change, for example, after experiencing a new type of treatment. Despite these limitations, a cross-sectional study design is recommended when the purpose of the study is descriptive and seeks to explore the prevalence an item of interest (Levin, 2006), which was in line with the study objectives.

4.6 Strengths

There are numerous strengths of the present study, especially surrounding the unique contribution to the existing literature. Firstly, the study focused upon perceptions of both potential causes and recovery factors within the same sample of women with lived experience of an ED. This allowed for correlation analyses to be carried out to explore relationships between perceived causes of an ED and related factors in recovery. It was established from the literature review that there is a dearth of this type of data. Furthermore, the methods employed in this quantitative study enabled data to be collected in a format that allowed for statistical comparison. As previously noted, research comparing the views of AN, BN and BED is very limited, and so this is a key strength of the study.

In addition to allowing for comparisons to be made, the survey design had a number of other strengths. Firstly, the survey items were created based upon the literature review rather than using a standard survey, which ensured that all of the factors of interest were incorporated. Providing a list of potential factors and measuring their endorsement with a consistent scale made the instructions easy to follow. The design also enabled endorsement of a large number of different social and psychological factors to be measured. Recovery status was self-reported, which was important to be consistent with aims of the research and ensuring the focus was on the perceptions of participants.

ED diagnosis was also self-reported, meaning some participants had received a professional diagnosis and others had self-diagnosed or reported a ‘probable’ diagnosis. It is a strength of the research that a professional diagnosis was not a requirement as it allowed women who had not accessed specialised treatment, or possibly not disclosed their difficulties to anyone before, to take part. A ‘probable’ diagnosis was reported by 13.2% of participants. These hard to reach women have often been overlooked in other research.

The anonymity available through the use of an online format appears to have encouraged more women to participate, as most completed the survey without leaving any contact information. It is also unlikely that social desirability had an impact on the responses. As previously outlined, the use of an online method of data collection also maximised participation by removing geographical boundaries. The data collected was exported from the online platform and then imported into the data analysis software, removing the opportunity for manual input error.

A multitude of different psychological and social factors were perceived to be important causal and recovery factors across all EDs. Significant differences among AN, BN and BED, and between the participants in the recovered and non-recovered categories, were also found. These findings may have important implications for clinical practice.

4.7 Implications

The findings from the present study have a number of clinical and theoretical implications. The perception that their ED helped them to cope with negative emotions was the strongest predictor of recovery status, implying that viewing an ED as serving a positive function may be a barrier to recovery and something that needs to be understood and addressed in treatment. The perceived value of AN constitutes part of the well-known cognitive-interpersonal maintenance model of AN (Schmidt & Treasure, 2006), but the present study suggests that it should also be incorporated into theories of the maintenance of BN and BED. Whilst the MANTRA method of treatment includes several exercises aimed at targeting the value clients place on their AN and their pro-anorexia beliefs (Schmidt et al., 2014), these present findings suggest that adapting these exercises for inclusion in the treatment of BN and BED may be beneficial for improving treatment outcomes. The potential impact of addressing the perceived positive function of BN and BED in treatment is an important area for future research highlighted by the present study.

The findings in relation to self-motivation suggest that it plays a key role in recovery from an ED, supporting the theory that interventions that seek to enhance motivation should be incorporated into ED treatment programmes. This is an important contribution to the literature, as studies so far into the effectiveness of these techniques have not provided definitive results. Adaptations of motivational interviewing have been trialled in the treatment of EDs but without consistent evidence of effectiveness (Knowles et al., 2013).

Motivational enhancement therapy has been found to improve symptoms and readiness to change in BN, but only to the same extent as CBT (Treasure et al., 1999). It is suggested, based on the findings of the present study, that understanding how to effectively incorporate motivational enhancement techniques into treatment should be an area of continued research.

Despite the similarity across the diagnostic groups in relation to using their ED to cope with emotions and self-motivation, diagnostic differences were also found that may have important clinical implications. Firstly, it appeared that women with BED were more likely than women with AN to have been bullied about their weight or appearance, and were more likely than women with AN or BN to perceive tackling issues around food and body image to be helpful for recovery. These findings support research that has found higher body dissatisfaction in people with BED than AN or BN (Fassino et al., 2004) and imply that body dissatisfaction should be considered when developing theories of the onset of BED. It therefore appears that a focus on improving body image should be central to the treatment of BED, however, this inference requires further research. Secondly, the results suggest group therapy and support groups were preferred by women with BED, which has clinical implications for the use of peer support, alongside individual treatment programmes, for women with BED. Finally, participants with BN were found to be less likely than those with AN to endorse having support from family, friends or a partner, or having family or partner involvement in treatment, as helpful for recovery. This finding could have implications for the relative importance of facilitating a social support network across different ED diagnoses. Overall, these diagnostic differences demonstrate that a transdiagnostic theory of onset and maintenance may overlook variations that could be critical to improving treatment efficacy.

4.8 Conclusion

The present quantitative study used an anonymous online survey to ask women with lived experience of an ED about their perceptions of potential causal and recovery factors relevant to their ED. Participants’ responses were also compared based upon the self-reported categories of recovery status and ED diagnosis.

The variety of factors leading to the onset of an ED endorsed by these participants is consistent with the multiple-causality models currently proposed in the ED literature. The findings from the present study suggest that psychological factors of low self-esteem, ineffective coping strategies and perfectionism were seen as causal factors across AN, BN and BED. While psychosocial influences of EDs were demonstrated across all of the diagnostic groups, there was some variability by diagnoses. It appeared that women with BED, and sometimes BN, were more likely to have experienced bullying about their weight or appearance and to attribute this to the onset of their ED. Using the ED to feel a sense of control featured more heavily in AN, but still to an extent in BN, but was not considered to be a causal factor for BED. There were also some diagnostic variations in terms of potential recovery factors. Participants with BED were more likely to endorse support groups, potentially as they were also less likely to have experienced specialised ED treatment, and to endorse tackling issues around food and body image in treatment.

Self-motivation, along with addressing different underlying causes of an ED, and in doing so treating each person as an individual, were found to be the most important factors for recovery across all diagnostic groups. It also appeared that working to increase self-esteem, and to change the client’s perspective of their ED during treatment to one in which it is not considered to serve any positive function, and teaching more adaptive strategies may increase the chances of recovery.

CHAPTER FIVE: ‘Well You’re Obviously not Anorexic’: A Qualitative Investigation Into the Experiences of Women With Lived Experience of an Eating Disorder

5.1 Introduction

This chapter presents the qualitative study, which utilised interviews with women with lived experience of an ED. Although the quantitative study also collected data from the perspective of women with lived experience, quantitative methods are generally considered to be more restrictive than taking a qualitative approach. The quantitative study, presented in the previous chapter, provided the opportunity to break down concepts into statistically measurable constructs and examine the relationships between these constructs (Punch, 2003). This method enabled hypotheses generated from existing literature to be tested, which is important to substantiate theories, but restricted the opportunity for new insights and the exploration of unexpected topics (Willig, 2001). Qualitative research has the ability to explore experiences in more detail, and to consider how lived experiences are perceived and understood (Willig, 2001), consistent with the project objectives and philosophical position. Qualitative methods can also allow for complexities such as changes over time and variations dependent on context to be explored (Snape & Spencer, 2003), which, in the present project, was not possible to ascertain through the quantitative study. Taking a mixed methods approach, by conducting qualitative research alongside the quantitative study, allowed the creation of a more detailed and holistic picture that could not have been captured by the statistical methods alone (Ritchie, 2003).

The qualitative study presented here collected detailed participant narratives, allowing the women to discuss their experiences of their ED holistically, from onset to recovery, without being restricted to factors predetermined by the researcher. Unlike the quantitative study, participants were also able to articulate links between factors, describe different aspects of a factor, and were asked about maintenance factors and their experience(s) of treatment.

The present chapter begins by recapping the findings from qualitative research conducted from the perspective of those with a history of an ED. The aims and objectives of the present study are then described. The methods employed are explained, including the way in which the interviews were conducted, and details about the participants involved are outlined. Next, the data analysis undertaken is described and the results are presented. Finally, the findings are discussed in reference to the aims and objectives, and existing literature, and the strengths, limitations and implications of the study are set out.

5.1.1 Key Findings from the Qualitative Literature

The existing qualitative research focusing on a person's perceptions of the causes of their ED (reviewed in Chapter 3) has identified a range of psychological and social factors, which are summarised here. The most commonly perceived psychological causes identified through qualitative research were: a need for control (Button & Warren, 2001; D'Abundo & Chally, 2004; Dignon et al., 2006; Fox & Diab, 2015; Patching & Lawler, 2009; Redenbach & Lawler, 2003; Rossotto et al., 1996), low self-esteem (Dignon et al., 2006; Gulliksen et al., 2017; Lacey et al., 1986; Redenbach & Lawler, 2003; Rossotto et al., 1996; Tozzi et al., 2002), perfectionism (Granek, 2007; Gulliksen et al., 2017; Rossotto et al., 1996; Tozzi et al., 2002) and having difficulty managing emotions (Fox & Diab, 2015; Rossotto et al., 1996). The most common findings in relation to social or environmental causes were: sexual abuse (Dignon et al., 2006; Granek, 2007; Lacey et al., 1986; Rossotto et al., 1996; Tozzi et al., 2002), a poor relationship with or bullying by peers (Hsu et al., 1992; Lacey et al., 1986;

Nilsson et al., 2007) and a poor relationship with parents (Hsu et al., 1992; Rossotto et al., 1996).

A small number of studies have explored maintenance factors from the perspective of participants with lived experience. Similar to the etiological findings, using their ED as a way of coping with emotional distress (Gulliksen et al., 2017; Jenkins & Ogden, 2012; Lacey et al., 1986; Rossotto et al., 1996) and as a means of feeling in control (Button & Warren, 2001; Rossotto et al., 1996) were frequently identified as maintenance factors. Media portrayals of the thin-ideal body type were perceived as reinforcing disordered eating behaviours (Dignon et al., 2006; Redenbach & Lawler, 2003). In AN specifically, the ability to restrict was perceived as increasing self-confidence through a sense of achievement (Gulliksen et al., 2017), but further diagnostic differences were not ascertained.

The most frequently discussed topics within qualitative research investigating client views on treatment were the importance of the therapeutic relationship, the characteristics of the therapist, and concern that there is an overemphasis on food and weight rather than psychological support (e.g. Beresin et al., 1989; Rance et al., 2017b; Rorty et al., 1993; Tierney, 2008). Having strong social support was the most commonly identified aid by participants for ongoing recovery, following or separate from treatment (e.g. D’Abundo & Chally, 2004; Federici & Kaplan, 2008; Nilsson & Hagglof, 2006; Pettersen & Rosenvinge, 2002; Tozzi et al., 2002).

As demonstrated in Chapter 3, qualitative research with women with lived experience of an ED is limited. Furthermore, several gaps have been identified. Of the research that has been conducted, etiology and/or maintenance have mostly been considered separately to treatment, rather than considering the whole experience of an ED holistically. This separation means the ability to draw links between the factors that an individual perceives to be causing or maintaining their disorder and what they find helpful in treatment is lost. Additionally, no qualitative research was identified that compared the views of participants within different ED diagnostic groups (AN, BN and BED) to ascertain whether there might be important differences that may also have implications for variations in treatment. Yet, as established in Chapter 3, quantitative research has suggested there are diagnostic differences in causal factors, such as body dissatisfaction (Bulik et al., 1995; Fassino et al., 2004) and sexual abuse (Waller, 1991).

5.1.2 Aim and Objectives

While both studies shared the same core aim of the overall project, the purpose of the present study varied from the quantitative study in several ways that broadened the scope of the overall research project. By collecting an in-depth account of each individual's experiences and motivations relating to their ED, the focus of the study extended beyond causal and recovery factors to also include perceived maintenance factors and unhelpful experiences in treatment. Furthermore, recovery status was determined using the four survey options rather than two categories, to allow comparisons to be made among recovery stages. The aim of the qualitative study, therefore, was to gain a better understanding of the experiences, motivations and views of a sample of women with lived experience of an ED, particularly relating to the onset, maintenance, treatment and recovery of their disorder. The aim was broken down into four objectives:

1. To explore the factors participants perceived to have caused and/or maintained their ED.
2. To explore the experiences participants had with treatment, and the factors they perceived as helpful and unhelpful for improvement and recovery.
3. To investigate any differences in the views or experiences of participants at different stages of recovery.

4. To investigate any diagnostic variations in the views and experiences of participants.

5.2 Method

5.2.1 Participants

All of the participants in this qualitative study had previously completed the online survey that is also part of this thesis. The recruitment for and results of that survey were described in Chapter 4. At the end of the survey there was an optional question asking for the participant to provide their contact details if they were willing to take part in any further research. Initially, all the eligible participants who completed the survey and provided contact details were informed of the interview and asked if they were interested in participating.

The sample size required for qualitative research is dependent on the quality of the data, that is, if rich data is received from each participant then fewer will be needed (Braun & Clarke, 2013). Guest et al. (2006) suggested research that aims to investigate the experiences of participants rather than to achieve statistical generalisability may suffice with a sample as small as 12 interviews. In this study the concept of data saturation was used to guide the number of interviews conducted for participants in each of the diagnostic categories. Data saturation refers to the point at which the data collected no longer provides new information that further develops the findings, but a single process for how to achieve this point has not been established (Francis et al., 2010) due to the huge variations in research designs and study topics (Fusch & Ness, 2015). In the present study, data saturation was considered to have been reached when two consecutive interviews were conducted in which no topics were discussed that varied substantially from those already identified in prior interviews.

5.2.2 Interview Schedule

As discussed in Chapter 2, critical realism holds the position that experiences influence and shape our interpretation and perception of reality, and our construction of our own ‘social reality’. Thus it was anticipated that, in this study, each individual would identify different experiences and hold different views on causes, maintenance, treatment and recovery relating to their ED. A method was required that allowed each participant to share their own personal and nuanced narrative.

An individual, semi-structured interview was conducted with each participant. This method enabled a detailed understanding of each individuals’ perspective and experiences, which was important when researching a phenomenon in which awareness of the context of each persons’ personal circumstances is needed (Ritchie & Lewis, 2003). Individual interviews are considered to be a preferred method for sensitive topics as they offer privacy and can be responsive to the individual (Lewis, 2003). A semi-structured approach was taken as it provided open space for the participants to engage in personal narratives and discuss new or unexpected matters, while also ensuring enough structure for the research questions to be addressed (Galletta, 2013). The full interview schedule can be found in Appendix H.

The interview schedule was flexible to ensure that each interview covered the same core topics, as well as those topics initiated by the participant. The schedule consisted of open-ended questions: what their experience of their ED had been, what they thought caused their ED and why it was maintained, their experience of treatment, and their experience of recovery. There was also a question about the impact of their ED, which pertained to the larger COSTS Study rather than this thesis. Under each question there were a series of prompts to be used, if required, to elicit further information. The first question was always the same, but the remaining questions were not always asked in the same order to ensure a natural flow. Additional, spontaneous questions were asked in response to the narratives participants gave. The use of yes or no answer questions was kept to a minimum. The wording of prompts was carefully considered to avoid leading questions, and linked to what the participant had previously said. For instance, rather than asking “did you have low self-esteem?”, a participant was asked, “you mentioned not feeling good enough, what would you say your self-esteem would have been like throughout?”. As suggested by Braun and Clarke (2013), a ‘clean up question’ was used at the end of each interview, such as “is there anything else that we haven’t talked about that you think is important to mention?” This ensured that participants were not restricted to only discussing topics that were asked about directly.

5.2.3 Procedure

5.2.3.1 Prior to the Interview

It has been suggested that semi-structured interviews should be conducted face-to-face rather than over the telephone in order to be effective, due to the interactive and flexible environment needed (Legard et al., 2003). It is suggested a lower level of rapport is built over the telephone, as interviews were found to be shorter with less collaboration between the interviewee and researcher compared with a face-to-face setting (Irvine et al., 2013). Although not being in a shared space can limit some interactions, real-time online video communication tools allow access to participants who would not otherwise have been able to take part, and have been found to yield similar levels of rapport and quality of data as in-person interviews (Deakin & Wakefield, 2013). Oates (2015) concluded Skype to be a viable alternative to face-to-face interviews that allows interviewees to be relaxed in the comfort of their own home.

To maximise rapport with the participants in the present study, effort was made to complete as many interviews in person as possible. For situations when meeting in person was not feasible because of geographical location, interviews were conducted over Skype and Facetime. Ten interviews were carried out in person in Christchurch, two were conducted in person in Auckland, five were carried out over Skype and one was conducted using Facetime. No differences in the quality of the interview data were evident based on the means of data collection. Interviews in Christchurch were conducted in a private office in the Department of Psychology on the University of Canterbury campus. Interviews carried out remotely were conducted from the same office to maintain a quiet environment. Interviews in Auckland took place in a private room at the University of Auckland's Department of Psychological Medicine.

Building rapport and trust with participants is extremely important, and begins immediately at the first meeting (Legard et al., 2003). Thus, before beginning each interview in this study, the interaction began by thanking the participant for coming, personal introductions and beginning an informal conversation to set a relaxed and friendly atmosphere. Participants were then provided with the information sheet and consent form (a copy of which can be found in Appendix I). By signing the consent form they also gave permission to have the interview audio recorded. Audio recording was chosen over visual recording to protect anonymity. Questions to the interviewer were answered with honesty but no personal opinions were expressed to avoid influencing participant responses during the interview. Participants were advised that any identifiable information would be removed from the interview transcripts and only small unidentifiable quotes would be published, that they were to treat the interview as a separate entity to the survey, and that this was an opportunity for them to tell their story so it would be open for them to do most of the talking.

5.2.3.2 Data Collection Process

All interviews were audio recorded using a Sony IC Recorder PX470. Audio recording is recommended as best practice for semi-structured interviews as it ensures the participants' own words are captured in their natural form (Legard et al., 2003). Trying to make notes loses rapport through loss of eye contact and not engaging directly and does not capture as much rich data (Braun & Clarke, 2013). The interviews ranged from 20 minutes 38 seconds to 1 hour 54 minutes 22 seconds, with an average length of 54 minutes 38 seconds.

During the process, notes were made as a personal reminder of any points for which further elaboration or clarification was desired, and of any meaningful hand gestures or changes in body language that would not be captured by the audio recording. Active listening cues were utilised to show interest and to encourage them to continue where appropriate. Several moments silence were also left before moving on to the next question to ensure that the participant had finished speaking and to encourage her to continue if there was anything else she wanted to add. Participants expanded on their points numerous times, showing it to be effective. If there appeared to be something of a sensitive nature touched on early in the interview, a note was made to return to that topic later, once stronger rapport had been built.

A small number of participants became tearful during the interview, which was anticipated as a possibility. As advised by Braun and Clarke (2013), they were given time to express their emotions, rather than the interviewer becoming overly anxious and trying to stop the interview. Each time this occurred, once a moment had passed, the women continued to tell their experience without the need to confirm if they were okay to continue. No participants showed signs of distress on conclusion of the interview and several participants advised that they found sharing their views a helpful experience. Once the interview was complete, all participants were thanked for their time and involvement and those who had travelled were reimbursed with a $30 fuel voucher.

5.2.3.3 Transcription

The files were transcribed verbatim by the researcher (RW) and the documents were password protected. The transcription process involved producing as thorough an account of the interview as possible, including stutters, pauses, non-semantic sounds, emphases on particular words, changes in pitch, tone and volume, and changes in body language or gestures that had been noted down. Any identifiable information, such as names and job titles, was removed and substituted with a general note of what the information referred to so that the meaning was still clear. Once the transcriptions were completed, the participants who advised on their consent form that they would like a copy of their transcript were contacted to confirm their preferred format. The participants who requested their transcript be password protected were texted the password separately for additional security. All participants were requested to advise if there were any inaccuracies of fact by a certain date. No changes were requested. Each transcription was assigned a pseudonym using an online random name generator, unless the participant requested a certain name, to maintain anonymity whilst stressing the personal nature of her experience.

5.2.4 Data Analysis

5.2.4.1 Ontological Considerations

From a critical realist position, being aware of the role of the researcher throughout data analysis is vital, as the findings are the researcher's interpretations of the participants' perceptions (Danermark et al., 2005). As humans, researchers are influenced by their own experiences and understanding of the world (Clarke & Braun, 2018; Snape & Spencer, 2003) and there is a risk that researchers will project their own views when analysing the data, particularly when the data is ambiguous (Boyatzis, 1998). Reflexivity means the researcher paying close attention to their own views and experiences and how their choices could be influenced, and monitoring it closely to minimise any possible impact (Berger, 2015). This was particularly important to consider when making decisions, and began prior to analysis. As previously explained, the researcher began informal conversations with participants prior starting the interview. In addition to creating a relaxed atmosphere, this sought to minimise any perceived power imbalance. During the interviews, participants were encouraged to do most of the talking and to guide the conversation. Information about whether the researcher had a history of an ED was not disclosed to try and minimise participants' assumptions about the researcher's level of understanding. Attempts were made to approach each interview without any expectations based on previous interviews. Being reflexive also involves acknowledging that factors such as age and gender may have influenced interview responses and how comfortable participants felt sharing information (Berger, 2015). It is not possible to create a research design that can control all potential influencers (Danermark et al., 2005).

Throughout the analysis, analytic memos were kept to document thoughts and reasoning, as part of the reflexive process. Furthermore, peer consultation was carried out at two different stages of the analysis, the process of which is described in more detail in the next section. Also, each theme is presented using direct quotes from participants, to allow the reader to see the data from which interpretations were made and whether or not they would infer the same.

5.2.4.2 Reflexive Thematic Analysis

Thematic analysis covers a range of approaches to analysing qualitative data by identifying themes; more recently a version entitled reflexive thematic analysis was established by critical psychologists Braun and Clarke (2006). The method has commonly been used within psychological research to analyse interview data from clients about their experiences of counselling and psychotherapy (Clarke & Braun, 2018). As a method that can both reflect the observable reality and be used to investigate that which is occurring beyond the surface, reflexive thematic analysis is flexible to fit within different philosophical positions, including critical realism (Braun & Clarke, 2006). Braun and Clarke (2006) set out the six steps for conducting thematic analysis that were followed in this study:

1. Familiarising yourself with the data;
2. Generating initial codes;
3. Searching for themes;
4. Reviewing themes;
5. Defining and naming themes; and
6. Producing the report.

The first stage of becoming familiar with the data began when transcribing the interviews. Formal analysis began by listening to each audio file again whilst reading the associated transcript. Accuracy was then checked whilst concurrently being reminded of each interview and beginning to be immersed in the data, before carrying out the initial coding. A code is a word or phrase used to label a piece of data that captures the essence of that data and how it may be of use in answering the research question (De Santis & Ugarriza, 2000). It is accepted in the field of qualitative research that there is no single best way to code data (Saldana, 2009). The data-driven method of thematic analysis was used, deriving the codes solely from the content of the data without considering prior expectations from the literature, but stopping short of bracketing, an approach that encourages the reader to set aside all pre-existing knowledge.

As recommended by Saldana (2009), two cycles of initial coding were carried out. Firstly, manual coding was conducted using a pencil and paper by handwriting codes in the margins. As coding is interpretative, the process of coding previous transcripts can affect future coding decisions (Saldana, 2009). This possible influence is one of the reasons why a second cycle of initial coding was carried out. Each transcript was revisited by importing it into NVivo, a computer assisted data analysis software package that aids in the management of qualitative data by supporting rather than conducting the analytical process (Zamawe, 2015). A list of all the codes from the first cycle was used during the second cycle to see if any were very similar and could be merged.

As an interpretative method of data analysis, it is accepted that the codes generated from reflexive thematic analysis will vary dependent on the individual researcher. In line with Clarke and Braun (2018), a coding structure or codebook was not created as this goes against the research philosophy by implying that there is only one correct way of coding the data. Therefore, there was no measurement of coding reliability. It is however accepted that to ensure rigor in qualitative research, researcher subjectivity should be acknowledged and can be managed through reflexivity (previously discussed in this chapter) and seeking peer agreement (Morrow & Smith, 2000). Two transcripts were independently coded by a colleague, who was also a practicing clinician and so brought a different perspective. Both coded versions of each transcript were then compared to seek out any key differences in the codes chosen. Very minimal differences occurred and conversations took place about reasons for those few variations. These conversations did not result in changing any of the codes that had originally been generated, so it was agreed that additional cross-checking was not required. The whole process generated 67 codes, which can be found in Appendix J.

The next stages involved searching for themes, reviewing the themes, and then naming them. The codes were grouped together based on those which had a commonality to generate potential themes. The process was repeated several times until the groupings best reflected the narratives of participants. Some codes were found to fit within two themes or were linked to codes under a different theme. To visualise how each of the codes and themes were related to one another, a mind map was created. A small number of codes that did not fit under any of the themes were left from further analysis as they were not integral to the story. The final themes were reviewed by three colleagues to establish a consensus and ensure rigor.

Once the report had been written for each theme, the name was revisited to ensure it captured the key message.

5.2.4.3 Rigour in Qualitative Research

In their seminal work, Lincoln and Guba (1985) redefined the concept of rigour in qualitative research, determining that a different set of criteria is required to those used to address reliability and validity in quantitative research. They developed the alternative concept of 'trustworthiness' in qualitative research, consisting of: credibility (level of confidence in the findings), transferability (extent to which the findings are applicable in other contexts), dependability (extent to which findings are consistent or could be repeated), and confirmability (extent to which the findings are shaped by the participants rather than researcher bias). They proposed numerous techniques to incorporate these criteria into different methods, a number of which are present in the current research. Firstly, prolonged engagement is the process of spending enough time within the field to have an understanding of the central concepts. The researcher in the present study had completed a review of the background literature so had a level of understanding but further submersion in the topic may have increased preconceived ideas. Rather, focus was given to becoming familiar with the data prior to beginning the analysis by carrying out the transcription and listening back to the audio recordings before starting the initial coding. Secondly, peer debriefing is the concept of discussing ideas with peers to ensure they also perceive it relevant to the data. As previously described, this was achieved in the present study through multiple processes of peer consultation. Lincoln and Guba (1985) also emphasised the importance of reflexivity and triangulation, processes that are both discussed elsewhere in this thesis.

More recently, Morse et al. (2002) emphasised the importance of verification in qualitative research. The authors described the systematic checking, and confirming or altering the research process, as central to ensuring rigour. The concept of investigator responsiveness (the flexibility of the researcher) is proposed as central to verification in qualitative research. In the present study, reflecting back on each interview following its conclusion to consider how the researcher's words or presence may have influenced the interviewee, to learn for the next participant, and altering the grouping of codes multiple times to identify the key themes that best reflected the narratives of participants, demonstrates investigator responsiveness. Additionally, the thorough examination of deviant cases is a further validation strategy (Mays & Pope, 1995). Deviant cases were included within the present research, such as the discussion around one participant who reported that praise in treatment was unhelpful, which was contradictory to the majority of participants.

Furthermore, Braun and Clarke (2020), who established the method of analysis used here, stated that using the most appropriate method of data collection, data analysis and sample of participants are key to ensuring rigour in qualitative research. Thus, being transparent as to the methods used and the reasons for any decisions is central to demonstrating rigour. Throughout this chapter, clear explanations of the methods used in the present study, and the reasons why, are provided.

5.3 Findings

A total of 18 interviews were carried out, consisting of seven women with AN, seven women with BN and four women with BED. Details of participants can be viewed in Table 15. Although many participants advised they had received a professional diagnosis, the diagnostic category was self-defined. The participants' recovery status was determined by using their responses to the online survey. Recovery status varied across the three diagnostic groups. The average age of participants was 33.5 years, with a range from 16 – 51 years, similar the full sample in Study 1.

Table 15

Participant characteristics in the qualitative study

Pseudonym	Diagnostic Subtype	Recovery Status	Age (years)	Ethnicity
Daniella	AN	Still have a significant ED but somewhat improved	31	NZ European
Pippa	AN	Still have a significant ED but somewhat improved	18	NZ European and Other Ethnicity
Tracey	AN	Still have a significant ED but somewhat improved	19	NZ European
Helen	AN	Some symptoms of the ED but overall much improved	22	NZ European and Other Ethnicity
Maddie	AN	Still have a significant ED but somewhat improved	18	NZ European
Jan	BN	Some symptoms of the ED but overall much improved	42	Other Ethnicity
Anika	AN	Still have a significant ED but somewhat improved	16	NZ European and Maori
Beth	BN	Some symptoms of the ED but overall much improved	49	Other Ethnicity
Kelly	BED	Still have a significant ED but somewhat improved	43	NZ European and Other Ethnicity
Zoe	AN	Some symptoms of the ED but overall much improved	23	NZ European
Kay	BN	Some symptoms of the ED but overall much improved	47	NZ European
Alice	BED	Still have a significant ED but somewhat improved	48	NZ European
Millie	BN	Still have a significant ED but somewhat improved	23	NZ European
Christina	BN	Recovered from the ED	51	NZ European
Andrea	BED	Still have a significant ED but somewhat improved	39	NZ European
Miranda	BN	Still have a significant ED but somewhat improved	23	NZ European
Linda	BN	Some symptoms of the ED but overall much improved	42	NZ European
Catherine	BED	Recovered from the ED	49	NZ European

The women in this study had each been on their own individual journey and spoke of a range of different life experiences, starting in childhood through to their present day. While there were variations in their experiences and perceptions of their ED, there were also some distinct similarities. Seven themes were identified through the process of thematic analysis: perceptions of being in or out of control, “people always compliment you for losing weight”, difficulties in being one’s true self, judging oneself negatively in comparison to others, emotion regulation, misconceptions of what a ‘legitimate’ eating disorder looks like, and a change in perspective. A summary of the themes and the codes that constituted each theme is illustrated in Figure 1. The majority of the themes spanned across causes, maintenance, treatment and recovery, demonstrating the holistic nature of the participants’ experiences. In the next sections, each theme is described incorporating direct quotes from participants to illustrate the theme. The themes are not presented in order of hierarchy of importance or frequency, as no theme was determined to be more dominant than another. Rather, the order is consistent with the journey of the participants, i.e. with the themes that were more frequent during onset and maintenance presented first, followed by the themes that featured more heavily during treatment and then recovery (whilst accepting that, as previously stated, themes did span across these different stages of an ED).

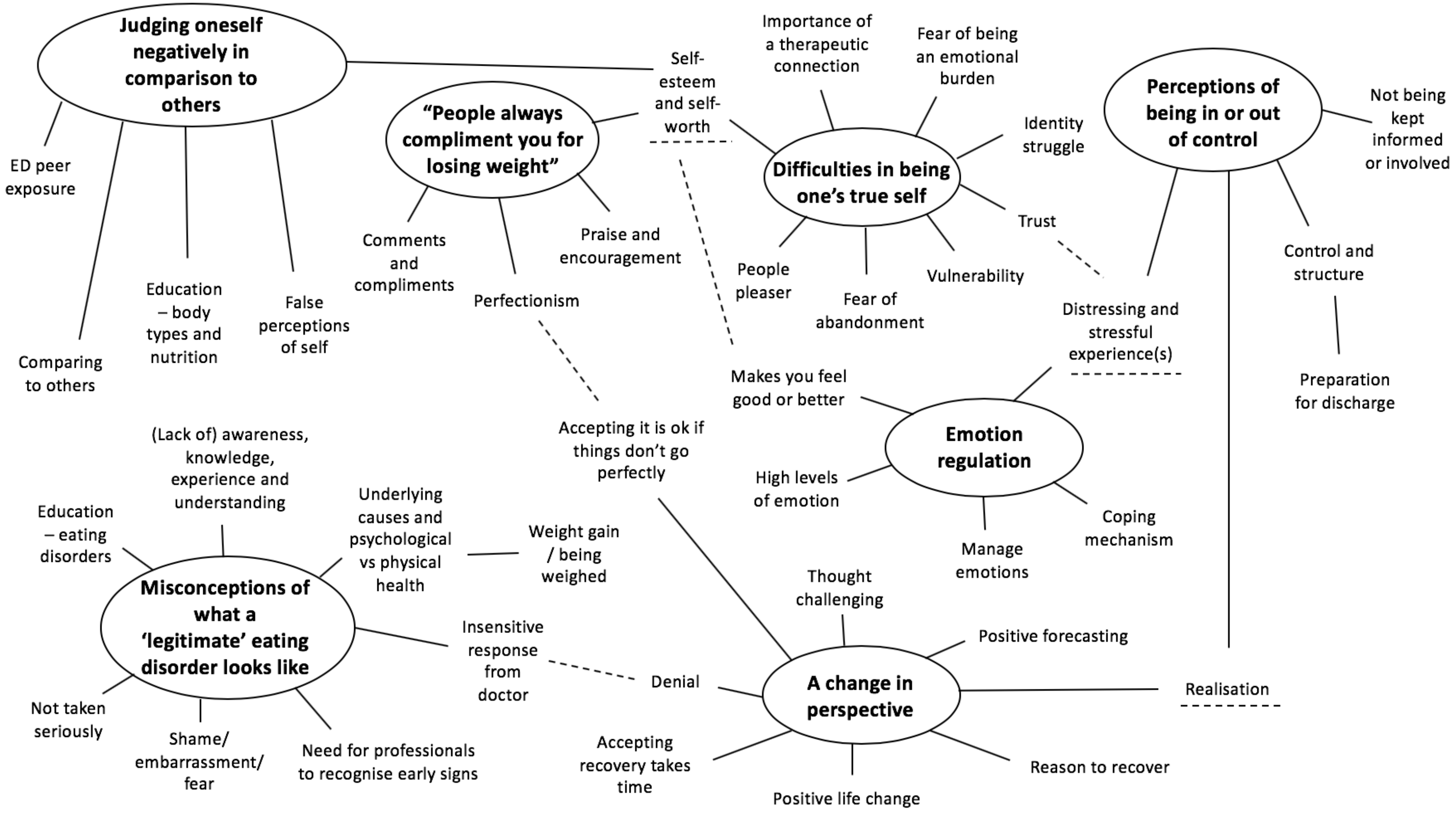

Figure 1: Summary of the seven themes and the codes that constituted each theme

Note. Codes that were grouped together to form a theme are illustrated by a solid line. Links between codes are illustrated through the use of a dashed line. Codes that sit within multiple themes are underlined with a dashed line.

5.3.1 Theme 1 – Perceptions of Being In or Out of Control

As discussed in Chapter 3, control is widely accepted as a causal and maintenance factor in AN in both qualitative and quantitative studies. AN is thought to address the need to control an aspect of life by generating perceptions of having some form of control, and weight gain represents a loss of that perceived control (Slade, 1982). It was evident that perceived levels of control had a central role in the experiences of participants in this study. They spoke about needing to feel they had power to influence their own lives, and their struggle with feeling out of control. The topic reoccurred throughout their recollections of their journeys, spanning the onset and maintenance of their disorder, and treatment and recovery. Participants focused on different aspects of control at different stages of their ED. Three sub-themes therefore were identified: ED as a means to increase perceived levels of control, being controlled by the ED – a maintenance factor or catalyst for recovery, and perceptions of control as an influence on engagement and success in treatment.

5.3.1.1 ED as a Means to Increase Perceived Levels of Control

Participants spoke of feeling like their life was out of their control and that food intake or weight was the only thing they had control over, consistent with other qualitative studies (e.g.Dignon et al., 2006; Redenbach & Lawler, 2003; Tozzi et al., 2002). High school was a particularly vulnerable time for the majority of study participants who described struggling to juggle an active social life, romantic relationships, studying and exams: “It became kind of a control thing because everything else was so hectic... the only thing... I really could have control over was my food” (Pippa). For some, the academic pressures were combined with an uncertainty over their future: “I didn’t know what I wanted to do when I left school. Yeah, probably just uncertainty and then wanting to get control back in my life” (Maddie). The need to feel they had control over something was therefore perceived as contributing to the development of their ED.

Several participants, all of whom had BN, explained how going through early puberty made them feel uncomfortable in their own skin as changes were happening to their body that were both uncontrollable and not yet happening to their peers. Whilst not being perceived as a direct cause, early puberty was described as intensifying feelings of a lack of control. This may provide some support for the conclusion that early menarche can be a risk factor for an ED when experienced in combination with other factors (Stice, 2002). Kay talked about her experience of early puberty and how, as her body shape changed, she began receiving attention from men that made her feel uncomfortable at such a young age. This left her feeling unhappy with her body, especially those parts that had changed: “I was always wanting– the fact that I couldn’t control what my body looked like, so there was a lot about control... just wanting to get rid of the boobs and the bum”. Although Kay described wanting to change her body, her emphasis was on the desire to regain control of both her appearance and the way people, in particular men, treated her. Dealing with the physical changes, and the social changes these bring, provides another dimension to the already established difficulties of adolescence. For those experiencing early puberty, it exacerbated the perceived need for control. Millie talked about her body changing and how her weight was the only aspect of herself she felt she could control: “You get your boobs earlier which are like fat ... so a little like oh you can’t change how you look but you can change your weight, you know, you can’t change your smartness but you can change your weight”.

Feeling a lack of control and using the ED to try and regain some form of control was also triggered by traumatic events. Beth talked about wanting to regain control over her body and the situation after a difficult relationship with a much older boyfriend during her teens, which also caused conflict with her parents. Kelly experienced childhood sexual abuse, which left her feeling out of control: “I think control’s a big deal and I think that also goes back to the abuse when I was literally out of control over my body, erm, and I felt out of control of my emotions too”. Several other participants also experienced abuse but they did not mention how it impacted on their perceived levels of personal control. Instead they talked about other effects, which will be discussed elsewhere as part of Theme 4, emotion regulation (section 5.3.5).

As well as life events causing a perception of not having any control, it was also believed by some participants that they had a particularly high need to feel in control. For example, Jan referred to her “personality” and said:

> I cannot deal with uncertainty, so I like to have things under control and make a plan A, B, C, D, E, F, G until, you know, just to make sure that things are going well, so that causes me quite a lot of stress... I feel tired or stressed... my food intake is something that I–I perceive that I could control.

Overall, participants described having an intense need to feel in control, which was further enhanced by events and experiences such as puberty or abuse. Participants also described experiencing high levels of stress when things did not go as planned or felt out of control. Their need for control was believed by many to be a cause of their ED, and they described using their ED to increase their perception of being in control as a maintenance factor.

5.3.1.2 Being Controlled by the ED – A Maintenance Factor or Catalyst for Recovery

Despite using their ED to feel in control, several participants also described, after a period of time, having the realisation that they were not actually in control of their ED and, in fact, their ED was controlling them. Patching and Lawler (2009) described the initial sense of having some control being lost to the disorder. Similarly, study participants spoke of admitting that their ED was a false perception of control as a catalyst for beginning the recovery journey, for example Millie said:

> You think you have all this control but you actually have no control. I think that's the scariest realisation to come to is that you think that you're the one making the decisions and choices and stuff, when really you are just pretty much a body and like your mind is just owned by someone else.

Whilst Millie's recognition that her BN represented a loss of control was important in embracing recovery, as was the case with several others, some participants were aware of their lack of control but perceived this as a reason why they their ED was maintained. Andrea and Alice, both of whom considered themselves as still suffering from BED, described feeling like a different person takes over their body and being unable to control it:

> So I see them as two separate things and once this binge eating takes over there's no- there's no- I haven't learned to control it... it's almost like I'm tripping out... It's a bizarre feeling, that I'm such a logical person and I even understand what's happening to me yet after all these years I haven't got the tools to stop it. (Alice).
>
> I don't want it and I'm saying to myself in my head 'no!', you know, that internal battle that is 'no... stop! This is disgusting, I don't want this'... it's like someone takes over my own body. I just compulsively cannot stop until I'm literally like, I'm sick. (Andrea).

Andrea went on to talk about how feeling out of control with her ED and, in turn, losing control of how other people viewed her, intensified her feelings of being out of control. This culminated in Andrea's attempted suicide. For several others, recognising their intensive need for control and the associated stress, and learning to accept that they could not be in control of everything, was an important part of recovery. For example, Catherine explained:

> In terms of wanting to control everyone around me, how they act, how they do what they do, and in my circumstances just life in general, none of that is in my control and I have to accept that. If I accept that then life's a lot easier.

5.3.1.3 Perceptions of Control as an Influence on Engagement and Success in Treatment

Treatments in which participants were not listened to, kept informed or involved in decisions were perceived as unhelpful as they increased feelings of not having control. Zoe and Maddie, for example, struggled with family therapy as they felt their parents were overly involved in the treatment and decision making: "I didn't really like that because it was my mum and dad and they were like in charge and, I don't know, I didn't feel like I was in charge of my own recovery" (Maddie). Maddie already felt her parents had pushed her life in a direction she was unhappy with and she believed that may have been a contributing factor in causing her AN, and their over-involvement led to conflict rather than support. Jan, who, as previously explained, has difficulty coping with uncertainty and likes to plan, found a psychologist who didn't explain his reasons so unhelpful that she quit attending the sessions:

> I never understood why he was doing what he was doing... I think the fact that he didn't mention a specific plan or what was his idea, it made things hard for me... if he explained it then probably I would just go along with what he was trying.

While Maddie, Zoe and Jan's experiences of not feeling in control of their own treatment adversely impacted on their willingness to engage, Pippa felt that her experience exacerbated her ED:

> Everyone was talking about me, like my parents, the psychologist, like all talking about me but weren't listening to anything I had to say... it's like I don't–I don't wanna *[sic]* be controlled in that way... it just made me– the anorexia... it made it feel like it just took a hold of me even more. . . they just sort of like pushed things onto me which I had no control over... and it–it meant that that's why I then wanted to control my food.

In addition to the issues of control challenging the dynamic between participants and their therapist, heavily structured aspects of inpatient treatment were perceived to be problematic. During inpatient treatment, unless being tube fed, participants spoke about how meals were served at specific times every day, often four or five times a day, and being expected to eat precise portion sizes with very limited choice in the food they were given. Although they understood this was to ensure enough calories were being consumed, several participants felt that having too much structure around mealtimes was unhelpful as it echoed their experience of AN: "It's all measured, which is good but they're very focused on how much everything is... everything is measured exactly, perfectly, and nothing is out of line and that- that itself is a bit eating disorder like, you know?" (Tracey), and BN: "It was the same thing as the binging and purging cycle where you have an hour to eat, you know, like you are not eating when you're hungry, you are eating like on this strict schedule" (Beth). While institutional structures are designed to achieve weight gain, participants were critical of their effectiveness as a tool for long-term recovery. For some with AN, they voiced concerns that institutionalisation did not adequately prepare them to organise their own meals or eat without being supervised after discharge.

To summarise, perceptions of personal control was a recurring theme throughout the participants' journeys, whether they had AN, BN, or BED. Participants reported feeling a lack of control, particularly during high school (with academic demands, social pressures and, for some, early puberty) and after experiencing abuse. AN and BN helped to feel some form of control. Already struggling with perceptions of being out of control meant treatment in which participants didn’t feel in charge of their own recovery was perceived as unhelpful, and treatment that was too strict and measured around food was perceived as reinforcing behaviours associated with AN and BN. Realising they were experiencing a false perception of control, and that they were actually being controlled by their disorder, acted as a catalyst for recovery for some. For others with BED, at the time of the interview they felt unable to break out from the control their ED had over them.

5.3.2 Theme 2 – “People Always Compliment You for Losing Weight”

Previous quantitative research has found negative comments about ones appearance are associated with body dissatisfaction (Sweetingham & Waller, 2008), but study participants also spoke about the impacts that positive comments had on them throughout their ED. Participants noted that compliments were received on appearance, particularly weight loss, which they perceived to have influenced the onset and maintenance of their ED. Opinions surrounding the usefulness of compliments during treatment were also discussed.

Several participants reported losing weight prior to the onset of their ED and receiving compliments for doing so. Receiving compliments on their weight loss had a number of impacts for participants, which they believed contributed to causing their ED. Firstly, participants described compliments as a form of positive reinforcement, encouraging them to continue or increase their behaviours. Kay associated getting compliments with being liked and began to take her behaviours to the “extreme” in order to keep receiving them:

> I lost quite a bit of weight and everyone commented on how wonderful I was and from then on it was just extreme. Extreme diets. And I would lose, you know, I would be around 50 kilos and 164-165 centimetres so still within a slightly healthy range but

> I was hooked on people telling me I looked good and I thought that’s the only way I’m going to get people to like me.

Similarly, Millie enjoyed receiving praise on her weight loss at first, but she went on to explain how the comments fuelled her beliefs about the way people should look:

> At first it was sort of like the weight comments were like ‘oh you look good you’ve lost weight’ which people stupidly say in this day and age, erm, and I was kind of like ‘cool’, I kind of liked those comments like at first... It reinforces that like skinny is good, fat is bad, this is how you should be.

Focusing on weight loss when evaluating appearance was seen to reinforce the thin-ideal body type, as “people always compliment you for losing weight, no-one ever compliments you for looking good if you are carrying 20 kilos extra” (Alice). Receiving compliments on weight loss was internalised by some as proof that people monitor the weight of others and have expectations of what it should be. They then felt pressure to meet those expectations, as Helen explained:

> You get all this influx of information from everyone around you being like ‘wow you’re smaller’ and you’re like actually no wait, people do notice and so I need to be careful and I need to like make sure I live up to that standard.

For some, the belief that people pay close attention to changes in weight was perceived as a reason their behaviours intensified to become an ED, and for others it led to a fear of weight gain that maintained an already developed disorder. Positive comments focusing on the body, not just following weight loss, were linked to feeling pressure to maintain the thin ideal figure. This is similar to the complimentary weightism phenomenon, in which positive comments increase body dissatisfaction for women as they demonstrate being valued based on appearance (Calogero et al., 2009). Pippa spoke of feeling as though she had been placed on a pedestal and how that impacted on her:

> I've always had ... people a lot coming up to me being like 'ah my god you have such a perfect body' like 'ah I wish I looked like you'... put me on a stand almost... and then it started to get to me that like I ... needed to be this sort of certain way for people.

Pippa described a perceived pressure to maintain the appearance that people had become accustomed to, reflecting Helen's previous comments of feeling she needed to live up to perceived expectations. There was also a suggestion that there was a fear of negative repercussions should they fail to reach or maintain these standards.

From a different perspective, Alice described the effects compliments had on her and how that maintained her BED. She speculated that the positive feelings triggered by receiving a compliment may enhance a sense of loneliness: "maybe when I'm really happy and someone will pay me a compliment, because I don't have anyone... because I don't have a partner and I don't get to share that with anyone, I go for comfort and food again" (Alice). This touches on a link between food and comfort, which is expanded upon in section 5.3.5.

Alice also referred to "self-sabotage", believing that when she has been eating healthily her ED takes over. Similar to the idea of self-sabotage, Zoe talked about receiving praise during treatment and how that maintained her AN:

> I think sometimes when I did try to get better I didn't like ... a lot of praise, like a huge amount of praise didn't do me well. I like- I mean yes acknowledge that it happened but if people are overreacting like 'oh that's awesome!' too much it freaks me out that I'm doing too well and that fired the eating disorder back up and things. I think that didn't help.

Others disagreed with Zoe, believing that they respond well to receiving praise and encouragement in their lives, such as Danielle: “at work I need praise and I just don’t get that so I feel like something’s missing, like at [previous employer] they always used to tell me how amazing I was”. It was suggested by Jan that different personalities need to be addressed in different ways during treatment to achieve the highest level of effectiveness: “I got a tough person and encouragement and–and–and that gave me the information I needed in the way I–I require for my personality”. Pippa described herself as a perfectionist and believed that to be why she would have responded well to compliments during treatment:

> [I]t should focus I think a lot more on like, actually the things you are achieving... because I mean that is a thing that a lot of people with eating disorders have, they are perfectionists and overachievers, so therefore if you make it more into a thing where this is something that you’re achieving and you’re doing really well... that would so much more play into the tendency of people.

Many participants referred to themselves as being a perfectionist as part of their identity. For example, Maddie said: “I’m quite a perfectionist, like quite rigid black and white thinking, just quite driven and determined”, and Jan explained: “I am an over-achiever, I’m a perfectionist”. Participants noted that being a perfectionist meant “setting really hard expectations” (Millie) and “a lot of pressure” (Miranda) to achieve, which they perceived to be a cause of their ED, in line with previous research (e.g.Egan et al., 2011; Granek, 2007; Nilsson et al., 2007; Rossotto et al., 1996; Tozzi et al., 2002).

Pippa explained that being a perfectionist meant a need to feel a sense of achievement and a sensitivity to criticism, as perfectionists “are people who feel quite quickly sensitive of feeling like they are doing things wrong”. Therefore, receiving compliments during treatment could also help to limit any feeling of failing, and reduce thoughts that it may be “easier to just perfect anorexia”. One way to limit the risk of feeling like they were failing in treatment, as discussed by Helen, was to select approaches based on the individual’s experience:

> Some of the breathing techniques and the meditative approaches that we did, rather than feeling like I was going into something new, I was going into something familiar that I have already touched on before and so it kind of gave me that, erm, bit of confidence that at least this is one thing that I know I can kind of do.

In summary, compliments about weight loss and physique were perceived to be involved in causing EDs by acting as a form of positive reinforcement of initial ED behaviours, promoting the thin-ideal body type, and suggesting that people notice changes in weight and evaluate others based upon it. Furthermore, increased pressure to meet expectations and self-sabotage on receipt of a compliment were seen as maintenance factors. In treatment, compliments were seen to risk triggering ED behaviours for some but were helpful for others by addressing their need to achieve due to perfectionism.

5.3.3 Theme 3 – Difficulties in Being One’s True Self

Participants spoke about the difficulties they faced in being themselves, either due to uncertainty over their own identity or a fear of what would happen if they expressed their true self. They discussed how this struggle to show their true self to friends, family, and professionals impacted upon their ability to access support and engage in treatment, therefore maintaining their ED.

A fear of abandonment was evident across the majority of participants. They explained feeling like they were unable to be themselves due to a fear that it would result in them being abandoned by others. Linda described:

> I don’t think as a small child that I truly believed that they loved me unconditionally which I guess always made me feel I could be abandoned... so I was quite controlled around my behaviours to a certain degree as well because part of me just thought if I do that they’ll abandon me... that sense of self-identity I think was really connected to... what I wrongly perceived would be necessary for me to be okay.

Like Linda, other participants talked about how their fear of abandonment impacted on their behaviour, and the negative feelings towards themselves that underpinned their concerns. Many spoke of constantly needing to please everyone, for example, Andrea said: “I had these two tapes that run in my head. The first would be you’re not good enough... and the second one would be you must please everybody and make sure everybody is happy so that they don’t leave you”. Christina also described not feeling good enough:

> I think that was a big thing, just not feeling (pause) not feeling I could be part of a–a group or a community, not feeling I would fit in, not feeling comfortable, not feeling that I was interesting enough or that people would like me for being just myself.

Rather than perceiving these fears to be a direct cause of their EDs, participants spoke about how their responses adversely impacted on their overall wellbeing. Behaving in a way to try to fit in and please people often led to putting the needs of others before their own, which meant neglecting their own self-care:

> I kind of like constantly feel like I need to always be there for everyone, I like always needed to, you know, if a friend was in need like I’d always need to be there for them so it meant I’d often put my friends, my family, my schooling, everything in front of actually my own health and wellbeing. (Pippa).

Pippa described how considering the needs and feelings of others meant she experienced “a lot of guilt” for being “the reason for someone else suffering”, leading her to refrain from asking for support. Some participants found it difficult to be open with others for fear that they would let people down, for example, Kay explained: “I am a people pleaser... so my personality... I’d feel like I’d let them down if they were thinking that about me and then realised I wasn’t that”. Others were afraid that being open with people made them vulnerable to hurt: “at no time would I allow myself to feel vulnerable, to allow people to know what was really happening with me” (Andrea). Not feeling able to open up to people was also perceived to cause difficulties in relationships: “my belief is that I found it very difficult to, erm, to let myself be vulnerable in relationships... I–I guess I was scared of being, erm, rejected” (Christina). Finally, there were also concerns amongst participants that sharing their emotions and asking for support would make them an emotional burden to others. Helen explained: “I’m more than willing to help others but when it comes to helping myself I’m very hyper aware of how my situation can impact on other people, how it can make them feel”. Participants, therefore, struggled to share their feelings with others and ask for help, allowing their ED to continue.

Having a fear of abandonment and not wanting to be an emotional burden also impacted upon responsiveness to treatment. Speaking of her counsellor, Helen said that it was important to her that “she provided me with a space [in] which I knew I could say anything I wanted and not be worried about emotional consequences on other people”. Similarly, Millie explained “because it’s their job they can’t– like you can’t be a burden to them”. It was important to participants to feel able to show their true self when receiving specialist support:

> Once I found the right counsellor that-that definitely helped me because she in fact in some ways, ahh, she was perhaps my initial realisation, albeit therapeutically, [that

> someone could] love me unconditionally, because I showed her some pretty dark sides... I showed her dark sides of myself and she didn’t go anywhere. (Linda).

Participants described the importance of a good therapeutic relationship, supporting the findings of existing qualitative interview studies (e.g. Button & Warren, 2001; Fox & Diab, 2015), including building a connection that allowed them to be open without fearing judgement or rejection. Millie again referred to that underlying fear that she could be abandoned: “99 per cent of the time you feel stable, that they’re not going to leave you, and I think that’s a really nice feeling that you have that bond”. Trust was an important factor in establishing a relationship, and something that took time to build: “it took a very long time for me to trust and be comfortable” (Helen).

In addition to hiding their true self from others, some participants talked about struggling to know their own identity at all. Christina talked of having “a lot of uncertainty over myself”, Daniella referred to herself as “just a nothing” and Linda recalled not viewing herself as a person: “it wasn’t through a confidence thing, it was almost just through a complete negation of self and that I was a body, that I was a woman”. A small number of participants discussed AN in relation to their identity. Mirroring the findings of Weaver (2005), they went on to describe how, once they were ill, they thought their AN was maintained as it became a sense of identity for them. Zoe said: “I think part of it was I didn’t know what or who I was or what to do without it”, and Tracey explained: “I was scared to let it go. It’s something that you hold on to and it’s just like this is me now and it kind of becomes your personality”. For some, developing a stronger sense of self was perceived to be a significant factor in their recovery. Christina perceived “starting life”, knowing who she was and how she fitted into the world, and the subsequent increase in her self-confidence, as important in her recovery:

> I’ve got heaps of self-esteem now, I– yeah, completely different person in that regard. I have a lot of confidence in myself and in my place in the world... without a shadow of a doubt... becoming a confident person was a huge part of my recovery”.

To summarise, throughout their lives participants described struggling to be their true self, for fear of not fitting in, being abandoned, uncertainty over who they were, not feeling good enough or a negation of any self-worth. Participants went on to explain how they focused on trying to please everyone and constantly putting the needs of others before their own, resulting in neglecting self-care and maintaining their ED. It was therefore important to participants that they were able to establish a trusting therapeutic relationship in which they felt they could show their true self without being a burden or being abandoned. A small number of participants believed their ED was maintained as it had become their identity, which made it hard to give up. An increase in self-confidence and sense of self was seen as helpful for recovery.

5.3.4 Theme 4 – Judging Oneself Negatively in Comparison to Others

Participants spoke of having a tendency to constantly compare themselves and their lives to other people. They discussed the ways in which they thought judging themselves against friends, women they see, media images and peers had impacted upon their ED behaviour, including onset, maintenance and recovery.

Daniella explained that, in her eyes, “everything is always grass greener on the other side”, mirroring the majority of participants who viewed themselves negatively compared with others. Kay explained that when she looks at other people “it’s always a strength-based” approach rather than looking for faults in others, but she will then judge herself negatively against them. Focusing on appearance, Alice also talked about how she would critique herself but not others: “that’s the least important thing in the world, how you look, and I would never judge anyone on how they look, yet I judge myself on how I look”.

When discussing the way they would compare themselves to others, the majority of participants specifically focused on their body size and shape. Daniella spoke of looking through magazines at female celebrities and Tracey described how she started looking at videos and images of women online, as well as girls she knew. She explained that she aspired to look like them, saying of one online video celebrity: “she looks so happy, she looks so healthy, she looks really good, I want to be like that”. She focused on a drive for happiness, referring to several girls as “skinny” and perceiving being thinner as being happier. Similarly, Millie voiced concern that believing there is an association between weight and happiness may be a causal factor in the onset of EDs, and that media imagery may be “selling that idea that skinniness is happiness”. Many participants believed women who were slimmer than them appeared happier and that if they looked more like these women, their happiness would increase too. Their eating behaviours, therefore, were initially intended to have a positive function but this anticipated happiness was never described as being achieved.

While Daniella and Tracey sought out imagery to compare themselves to, most participants who discussed media influence spoke of being exposed to or “bombarded by... images that are not really attainable” (Christina) within everyday media. There were opposing views on the current level of media influence. Millie considered the impact to be strong for her generation as she has “grown up with a lot of social media,” whereas Beth believed the focus when she was younger in the eighties was on being skinny but “today we have Beyoncé and we have... role models for young women that are different body shapes”. Several participants discussed the idea that altering misleading messages in the media, educating people about different body types, and teaching “that we all come in different shapes and sizes and that’s okay” (Linda) may help to alleviate the pursuit of the ideal body.

Rather than considering her tendency to compare herself to others as a cause of her ED, Anika believed it to be part of her illness, maintaining her behaviours. Helen also described “comparison to your peers, comparison to your friends, to people you admire” as a “trigger” for the reoccurrence of eating disordered thoughts and behaviours. She went on to explain how she believed depriving her brain of nutrients impaired her cognitive functioning and caused her to be unable to judge herself accurately. Several other participants perceived their ED and the state of starvation as causing an inability to think rationally. Some participants also spoke of having, or having had, false views of themselves, including in comparison to others. For example, Millie said: “I’ve always been, in my opinion, but now I realise not... but I always thought I was quite a lot bigger than my friends”.

For those participants who experienced inpatient treatment, they described a shared environment with peers against whom they would again compare themselves. Daniella noted that she “hated all the girls [because] they were skinnier” and she “wanted to be the skinniest”, Millie “heroised” her peers, and Tracey explained how copying her peers led her to learn more unhealthy behaviours. While these participants discussed aspiring to be like their peers in treatment as potentially fuelling their ED, being exposed to peers who were further along in their recovery was considered to be helpful. Being in an environment with peers who “share their experience, their strength and their hope” (Linda) was perceived as helpful, as it allowed them to see that recovery is possible and they were not alone.

In summary, participants described a tendency to compare themselves, their lives and their bodies to other women, including peers and media imagery. For the majority of women in the study, this act of self-comparison was perceived as maintaining their ED. Frequently, participants idealised the lives and appearance of others, articulating a common belief that thinness was associated with happiness. The majority judged themselves negatively, which was often a false view that some perceived to be the result of a cognitive impairment caused by their ED. A few participants stated that they would never judge others but, despite being aware of the double standard, they continued to critique themselves. For participants who experienced inpatient treatment, they were exposed to peers who they would compare themselves against. Drawing comparisons to peers was described as having both negative and positive consequences, depending how far along the journey to recovery the peers within the shared environment were.

5.3.5 Theme 5 – Emotion Regulation

The term emotion regulation refers to the way in which people influence the emotions they feel, and when and how they express them; processes which can be either conscious or unconscious (Gross, 1998). A connection between EDs and emotions was evident in both the onset and maintenance of all three diagnostic subtypes. Participants explained the different ways in which they perceived their ED to be interconnected with feeling, or attempting not to feel, certain emotions. For some, they also went on to explain how they believed considering emotion regulation in treatment has been beneficial.

Several participants described themselves as feeling particularly high levels of emotion, for example, Alice explained: “I am a bit of an extreme person, when I am happy I am really, really happy”. Linda referred to herself as an “emotional sponge”, who takes on the emotions of others around her. She went on to explain her belief that she did not have the ability to process all of those emotions, particularly as a child, because she never learned to do so from her parents, saying: “if your parents can’t manage emotions then they can’t mirror how to manage emotions”. Jan also spoke of struggling to understand and recognise different emotions, and believed her family “don’t have much emotional intelligence” for her to have learned from. She particularly talked about how this impacted on her during times of emotional distress, having experienced the loss of her brother at a young age, as well as physical and sexual abuse:

> With all these things that have happened, the way that I coped with things was not to... I usually don't cry or anything like that but I was bottling everything in, not telling anything to anyone, and I'd just keep it and keep it and keep it until one day things just exploded and that's when I found that an eating disorder was my friend.

Experiencing distressing or traumatic events was common among participants and many echoed Jan in terms of seeing their ED as a way of coping and, for some, as a positive addition to their life at points. Most commonly, participants mentioned being separated from a loved one at an early age, whether due to a bereavement, a breakdown of the family, or being removed from the family home for a period of time. Struggles within, and terminations of, intimate partner relationships were also frequently experienced as times of distress. Some participants also suffered sexual and/or physical abuse. A range of quantitative research has been conducted into the relationship between forms of childhood trauma and EDs, and a review proposed child maltreatment is a risk factor (Molendijk et al., 2016). Rather than perceiving these adverse experiences as causes of their ED, study participants described the emotions caused and their perceived inability to manage those emotions as being the important influence in their ED.

Participants recalled the ways in which they perceived their ED helped them to manage emotions. Zoe stated that, for her, AN "kind of blocks out any emotion", and Tracey described how her AN worked as a distraction from feeling any emotion or pain: "you just can't feel anything because all you're thinking about is food all the time... I didn't feel anything, like nothing hurt me anymore". Similarly, Kelly described how binge eating "felt like it blocked the bad emotions" and Catherine spoke of "binge eating anything to push the feelings down”. For Linda, binge eating was often seen as a means to be able to purge; an act she described as feeling as though she was expelling the emotions from her body: “it felt almost as though the emotions would then cling to the food and like by purging them it just felt like there was no other way of actually managing them”. Despite referring to their ED as “a bit of a coping mechanism” (Zoe) or a “coping strategy” (Pippa) for dealing with emotions, especially negative ones, many participants described using their ED to avoid facing the emotion rather than as a way of expressing or managing it.

Alternatively, some participants spoke of using their ED to generate positive feelings, often as a source of comfort, particularly for women with BN and BED. Alice explained that “food has always been a comfort” as it made her “feel good”. Miranda speculated that there may be a biological reason why it makes her feel better when she is experiencing certain emotions: “emotionally, if I’m feeling really sad or, erm, really mad sometimes, or depressed, I will definitely binge ‘cos *[sic]* it made me feel a bit better... It tastes good and it feels good and I guess it triggers endorphins”. Similarly, both Jan and Beth talked about experiencing a “high” from binge eating and purging.

Whether perceiving their ED as a way of blocking out negative emotions, or producing good feelings, participants talked in a positive way about what they saw as the benefits of their disorder. Jan referred to her BN as a “friend” and Tracey stated she “liked it”, demonstrating a positive relationship. Pippa went on to explain “that’s why it just continued for such a long time”, echoing the views of a number of other participants. She also perceived she “didn’t have anything else to use” to manage her emotions.

Learning alternative coping strategies and gaining a better understanding of their emotions was important to the participants for their recovery. Speaking of what she perceived as helpful in treatment, Jan said: “they gave me a list of emotions and, yeah, I try to identify what the emotion is, naming it and stay with it... [A] couple of years ago I learned what it was to be frustrated or to be anxious or to be the different, erm, feelings.” She spoke of how understanding each different feeling has helped her to know how to respond to effectively manage each one, for example recognising that she should sleep if she was feeling tired. Several participants talked about the importance of recognising the link between their ED and their emotions, and being more aware of the emotional cues that elicit certain disordered eating behaviours. Miranda perceived learning to “notice that emotion, and sit with that emotion, and kind of understand why that emotion is coming up” as a helpful way to “cope with those urges”. Similarly, Linda explained:

> [T]he food calls but I know now when it calls there’s something else going on, I know something’s not quite right, but the difference is, you know, I’ve got so many other means... I can now be vulnerable with people and tell them how I feel and share things that maybe I’m not that comfortable about, but I can also internally tolerate a lot more... The emotions can stay in there and they’re not going to hurt me.

Linda described a change in the way she perceived emotions, from something that she should hide from as they would cause her pain, to a sign of a problem that she could then look to manage. She also spoke of the benefit of now being able to share her feelings with other people to help her cope. Similarly, other participants mentioned a range of coping strategies they have found helpful in their journey towards recovery, such as talking to someone, taking a walk, meditation, mindfulness or having a relaxing shower or bath. Beth and Pippa both perceived art, and expressing themselves through art when they might not be able to do so through language, as particularly beneficial. Pippa explained:

> I found it really helpful to kind of, you know, draw the feelings that I was having go on in my head, because a lot of the time it’s not something you can really put into words, like the stuff which is congested up there and like how I was feeling.

In summary, participants spoke of experiencing high levels of emotions, especially what were perceived as negative emotions, often due to experiencing a traumatic or distressing event. An inability to effectively deal with these emotions was perceived as an underlying cause of their ED as the ED became a way to cope, either by blocking out negative emotions or by generating positive feelings that made them feel good or acted as a source of comfort. Participants felt like they had no other way to cope, for some because they never learned about emotions as a child, explaining why their ED was maintained for so long. Therefore, learning to understand different emotions, why they were feeling them, and healthy alternative coping strategies were considered to be helpful in treatment and for recovery.

5.3.6 Theme 6 – Misconceptions of What a 'Legitimate' Eating Disorder Looks Like

It has been widely recognised that there are a range of misconceptions about EDs, often stemming from a lack of understanding of EDs, and stigma associated with different body sizes. These misconceptions have resulted in a recent emphasis on efforts to correct longstanding myths or 'false truths' about the causes, symptoms, psychological impact, and who can be affected by EDs (Schaumberg et al., 2017). The present study highlighted the importance of misconceptions of what an ED looks like. Participants talked about their own experiences of misconceptions and the different ways in which these misconceptions were perceived to have impacted upon experiences of treatment.

Many participants described misconceptions that they believed the public held about the bodies of people with EDs and how this then impacted on their willingness to seek support. Millie felt society only recognised AN and she struggled to talk to people about her experience with BN as she believed her weight undermined acceptance of her ED:

> People only think of eating disorders as [affecting] skinny people and I think that's another thing that like society needs to learn, is that it's not just skinny people that have eating disorders, and that's where I have found it really hard to talk about it because, I know I'm not fat, but I know I'm not like stick thin skinny.

Similarly, Jan felt unsupported by her family, whose limited understanding of EDs she attributed to the false beliefs normalised within society: "people think it's about modelling, about bodies, and it's not like that. My family have no idea of my problem because they just don't understand it." Some participants, particularly with BN and BED, explained how they perceived the public misconception that everyone with an ED is severely underweight left them questioning the legitimacy of their illness. Thus, it acted as a barrier to treatment. Miranda took a long time to access treatment as she didn't realise she was entitled to it:

> There's like a lot of focus on... people with eating disorders only being like really skinny tiny girls and I think that is also a part of why I didn't get treatment until now, 'cos [*sic*] I was embarrassed that I didn't meet that, um, criteria ... I kind of didn't realise you didn't have to be like dying to get help.

Helen described not feeling worthy of treatment because she wasn't at a low enough weight, linking to the notion of low self-esteem: "once you're the sickest of the sick and then, right then at that point, you're good enough for, um, treatment". She therefore emphasised the need to "unravel that expectation we have of what an eating disorder looks like so that people feel validated [and] they feel that the state that they are in right now is sick enough to get help". There was also a concern that these misconceptions of EDs could result in people failing to realise their eating behaviour is "not normal" (Andrea) and "that it's actually an illness" (Jan). Miranda was particularly concerned about individuals with BED: "I know some people that struggle with binge eating don't even realised that it's... a disorder, they just think that they’re- that they just like food”. Furthermore, Jan went on to explain her belief that “the problem relies on education for the general population”. Jan’s belief that there needs to be more education around EDs, and the different types of ED, was echoed by several other participants, especially those with BN and BED.

For some participants, the belief that their behaviour was normal was reinforced rather than questioned when they raised their eating behaviours to a professional, in an attempt to seek help. When taken to see a psychologist, Maddie was dismissively told that “most pretty girls have anorexia”, reinforcing the stereotype. Kay also felt like her concerns were dismissed when she told her nutritionist that she would make herself sick and was told “we’ll keep an eye on it... and that was it really”. For these women, the healthcare provider at their first point of contact failed to refer them to specialist advice or treatment and instead made the women feel like their problems had been trivialised. Millie told a powerful story of what happened when she mentioned to her doctor that she had difficulties around food:

> [M]y doctor was kind of like because you’re not like on death’s door and skin and bone, therefore you can’t have this disorder, which is really, really hard ... She actually like laughed, like not a hahaha but like a ‘ha!’ kind of comment and then was like ‘well you’re obviously not anorexic!’ which was just horrible! ... I just shut down and was like cool so my problem’s not... a real thing, I can keep doing what I’m doing.

The response Millie received reaffirmed the denial she had about the existence of her illness; denial that a number of participants described facing. She was left feeling that her concerns were invalid, and was “scared to talk about it with people” in future. As well as experiencing difficulties in being taken seriously when they first approached someone for help, several participants believed misconceptions continued to influence some treatment professionals.

Andrea voiced her concerns that the psychological impact on people who are not an unhealthy weight is not considered by some professionals working within mental health:

> I worry about the medical profession not having an understanding of that and the psychiatric profession not having an understanding of it. Unless you see someone with their ribs poking out, you know, unless you see someone so frail... that's what you think when you think eating disorder, but you don't think about the absolute, yeah, just the mental energy.

The dismissive responses these women received were also perceived as insensitivity to how hard they found living with an ED and accessing help. For some, it was evident that the experience had a lasting effect, for example, Millie voiced the concerns she still had in speaking to people about her illness: "even this interview I was kind of worried, I was like... is someone else just going to, you know, shut down and pretend that it's not... a problem?"

Feelings of fear as a barrier to asking for help were common amongst participants, including fearing not being believed, not being taken seriously and of being judged, for example, Linda explained:

> I'd never ever, ever admitted to an eating disorder because I was too scared about the implications of that... in my head it was like 'they'll think you're a flipping nutcase, you'll never get this job, the doctor's going to judge you' ... And there's also that stigma... the idea that you see someone who's fat you just think... lack of self-control, lack of self-will, you know, how disgusting... so there's that as well that makes it really difficult.

The stigma attached to being overweight or binge eating that Linda talked about was referred to by several other participants, who described feeling embarrassment and shame. Perceiving stigma and shame as a barrier to accessing help was a prominent issue in a review of both qualitative and quantitative research (Ali et al., 2017). Christina explained that it took a long time for her to ask for help as she "didn't want anybody to know" because she was "very ashamed of it". Her feelings are echoed in those of Miranda, who went on to suggest that education about the existence of the different subtypes of EDs may help to break down that barrier to treatment:

> [T]he 'you can get help' sort of stuff, I feel it's very aimed at people who are very underweight, and for people who have EDNOS or bulimia who are usually either slightly overweight or like very rarely underweight, it kinda [*sic*] makes it more embarrassing 'cos you're already struggling with feeling fat... so, yeah, I think maybe just more stuff aimed at people who aren't anorexic.

In addition to being a barrier to reaching out for help, shame was also referred to as important in recovery. Participants explained how breaking down the stigma and the feeling of shame surrounding their illness lifted a burden from them, which they perceived as helping in their recovery. Having their ED medicalised removed the shame for participants with BN and BED. It helped to remove self-blame by correcting the misconception that "it's just people wanting to eat food and using that as an excuse" (Miranda). Jan perceived the staff at her eating disorders unit as helpful because "they see it as an illness, not as something that I should be ashamed of". She described how being able to assign reasons for behaviour and feelings, as well as knowing it was an illness, "helped me to take away the shame of things". Exploring the underlying causes was something that many participants perceived to be beneficial in treatment, consistent with existing qualitative research (e.g. Beresin et al., 1989; Jenkins & Ogden, 2012; Pettersen & Rosenvinge, 2002; Rorty et al., 1993; Tierney, 2008). Catherine went on to explain how removing the shame helped her to feel more at peace with herself, saying “just being able to be peaceful and kind, kinder to myself... and feeling lighter because I’m not carrying that shame... knowing this is a mental illness... this is not my fault”.

Some participants with AN were concerned that staff were focused on the physical and psychological benefits of weight gain but there was a relative neglect of attention to the emotionally distressing aspects of gaining weight. Those participants believed more psychological support was needed during the stressful time of weight gain and the immediate period after reaching their goal weight. Zoe said that while she agreed “you need to get to a certain weight before they can work on certain stuff”, she felt that she needed “a bit more support around that time when you’re putting on weight because that it the biggest mental challenge”. Her thoughts were echoed by Helen, who believed “it makes no sense” not to have support for her mental health during weight gain. Helen said she “found it so frustrating to be told like first we have to deal with what you’re struggling with the most without the psychological support, which is really what it is entirely, it’s entirely psychological”. Pippa described needing more psychological support after reaching a healthy weight:

> [A] lot of the time they very much just went on kind of if I was physically better rather than actually if mentally I was going ok ... yes maybe I looked physically fine but what was going on inside my head was completely wrong ... at a weight where I was like my supposed perfect ideal weight for height my mind has never been more sort of like controlled.

In summary, participants described experiencing misconceptions from the wider public and the medical profession, often surrounding their physical appearance. They spoke of the misconception that physical health is a reflection of mental health and, therefore, only people who are visibly underweight can have an ED. These experiences fuelled their perceptions of the stigma surrounding EDs, particularly BN and BED. They spoke about how these misconceptions manifested themselves as barriers to accessing treatment which allowed their ED to be maintained: not realising they had an ED, being unaware they could get treatment, not having their concerns legitimised by professionals and therefore not being referred to specialist treatment, and feeling shame and embarrassment. Participants believed that misconceptions can sometimes persist into treatment, with a lack of sufficient psychological support, particularly during weight gain or after achieving a healthy weight.

5.3.7 Theme 7 – A Change in Perspective

Under the previous themes, participants often spoke about the way they viewed their ED and themselves when discussing causal and maintenance factors. When considering recovery, it was evident that changes to these previous ways of thinking were central. Two main influences that elicited a change in perspective were identified, therefore this theme was separated into two sub-themes: an event or life change that motivated recovery, and acceptance and gradual changes achieved through treatment.

5.3.7.1 An Event or Life Change that Motivated Recovery

The key change that participants described was the way in which they saw their ED. Many women spoke of experiencing the realisation that the negative aspects of their ED outweighed the benefits, often through a key event that served as a turning point. Tracey explained how being told she was not allowed out of hospital to attend an event she had been looking forward to made her realise what her AN was taking away from her:

> They wouldn’t let me out of hospital, then I was like hey no this is serious, this is bad, I need to make a change, it’s ruined my life again... Probably missing out on so much, erm, of your life, and then realising that, erm, kind of hits you.

The most common realisation described was the level of risk their ED posed to their long-term health and mortality. Zoe referred to being tube fed as “a bit of a wakeup call” to the severity of her illness. Alice received a cancer diagnosis, which she believed made her “more aware” of her mortality, and incentivised her to try to recover. She explained that she has “got better reasons behind wanting to solve it now: cancer and a child! ... It’s a pretty big driving force”.

Establishing a reason to recover was described as important by several participants. Like Alice, several other participants spoke of their children as a driving force behind their recovery. Catherine stated that she wanted “to be a good role model for my kids”, and Kay explained: “I want to be healthy for my kids and I want to have grandkids... So [I] really focused on... what I wanted to do in life, how I wanted things to be, so I was really looking forward.” A few participants spoke about looking to the future, and Maddie detailed why she believed it is important for recovery to be able to make plans for the future:

> A lot of the time people’s eating disorders can keep going because people don’t know what they want to do with their life, like I met a lot of people with no ambition... I feel that finding a purpose or helping someone to find their purpose would actually be beneficial... [or] they don’t know what they’re actually recovering for.

Subsequently, the majority of participants noted that they had made changes in their life, including moving to a different job or location, ending and/or starting a relationship, leaving school and meeting new people. Whether the change was made intentionally or not, it was often linked to their new perspective, such as providing an environment in which they felt less pressure to be perfect or setting goals for the future. For example, Jan changed jobs to one in which she felt less pressure and stress, which aided her to change her outlook from being a “perfectionist” to “not trying to be perfect but do my best”.

5.3.7.2 Acceptance and Gradual Changes Achieved Through Treatment

For some, accepting that recovery takes time and breaking the journey down into small steps was considered to be an important part of treatment. Several participants spoke about the importance of accepting that there may be setbacks. Pippa explained that being told "you need to be 100 per cent better... felt so unmanageable and unrealistic", which she believed was especially hard for her due to being a perfectionist. A new therapist helped her to see things from, what she perceived to be, a more beneficial perspective:

> It kind of made me sort of be able to accept the fact that, yeah, ok... I do have an eating disorder but that doesn't mean that I can't, at some point, recover from it. Or even if I can't completely recover from it, that doesn't mean that my whole life needs to be in jeopardy... there are people who live with eating disorders and they are still able to have kids, they are able to have relationships, they are able to deal with most meal situations, it's just kind of something that lingers there a little bit.

Pippa found that viewing her ED as something that she could learn to manage removed the pressure of immediate recovery and the feeling of guilt if she had any setbacks. Catherine explained that "it's just finding peace... when you stuff up, because you do because you're human", and Kay talked about the importance of "not being hard on yourself if you are thinking about food because that's okay". Several participants also spoke about accepting that everything, including themselves, does not have to constantly be perfect.

Despite a consensus on the importance of being able to plan for the future as part of recovery, there were differing opinions on how they felt their ED should be viewed in the future. Daniella did not believe that it should be suggested to people that they may not be able to achieve full recovery. She explained:

> I did see, um, one of their women, which was [an] occupational therapist and that was to live with my illness. Now I'm not going to live with my illness for the rest of my life, I believe... I don't think I'll have anorexia my whole life... I just couldn't get my head around living with it. Like, why would you want someone to be okay with it?

For Daniella, being able to see a future in which she did not have AN was something for her to work towards. Several other participants spoke of finding positive forecasting and therapists who believed they could recover as helpful. For example, for Tracey an important factor to her was: "having really good support around me... people who just tell me that it is possible, just keep being told it's possible".

In addition to positive forecasting, thought challenging was another aspect of treatment that a few participants described as being helpful. They spoke of changing their perspective on their own thoughts, and in particular the importance of realising that thoughts can be inaccurate, as Helen stated:

> I think that was the simplest, most effective thing I could get out of my entire like seven months of counselling... just the sentence that she said, which was that thoughts aren't facts. Just because you think something doesn't mean that it's a fact and I think that was so important... my thoughts may not be reality, they're just simply feelings".

Miranda echoed these thoughts, by saying she found it helpful to learn to be able to "notice a reoccurring thought" and "identify the thought error".

In summary, participants found changing their perspectives on both their ED and themselves to be beneficial for recovery. Realising the extent of the negative consequences of their ED and the risk to their own mortality often acted as a trigger to self-motivate recovery. Having a reason to recover and setting goals for the future was also considered to be helpful. Participants also spoke about acceptance; accepting that they do not have to constantly be perfect, that recovery takes time and may involve setbacks, and that their thoughts are not always accurate representations of reality.

5.4 Discussion

The aim of this study was to gain a better understanding of the experiences and views of women with lived experience of an ED, particularly in reference to the onset, maintenance, treatment and recovery of EDs. Participants spoke about a range of different experiences, and a number of perceived causal, maintenance, treatment and recovery factors that they believed to be important in their ED. Through thematic analysis, seven themes were identified across the data: perceptions of being in or out of control, "people always compliment you for losing weight", difficulties in being one's true self, judging oneself negatively in comparison to others, emotion regulation, misconceptions of what a 'legitimate' eating disorder looks like, and a change in perspective. The findings highlight the complexity of EDs, with no discrete cause identified, rather an accumulation or interaction of often interrelated factors. The links between factors indicates the psychosocial nature of EDs, and, as a result, the complexity of providing effective treatment. In this study, factors considered helpful in treatment often related to acknowledging or alleviating causal or maintenance factors, with each of the seven themes identified spanning across etiology and/or maintenance, and treatment and/or recovery.

5.4.1 Causes

As anticipated, and in line with existing literature, the perception of being in or out of control was found to be an important concept in the development of EDs. Most participants self-identified with a desire to feel in control. For these women, it is suggested that if something negative happens that is out of their control, they respond in a way to compensate for this perceived loss of control. Subsequently, as proposed by Slade (1982) and expanded by Surgenor et al. (2002), AN and BN were seen as ways of increasing the perception of having some control in life through food intake and/or use of compensatory behaviours. Waller (1998) proposed that women with an ED who have experienced sexual abuse have a more external locus of control, signifying they perceive themselves to have little control over their life. The present study suggests that other forms of stress and trauma, in addition to sexual abuse, may have a similar impact on perceived control. However, not all participants who experienced abuse linked their experience to feeling out of control, implying that the link between abuse and EDs is more complex than intensifying a need to regain feelings of being in control. Many people go through trauma in their life but do not develop an ED, suggesting there are multiple causal factors involved for those individuals who do. Trauma, therefore, must be considered as a psychosocial risk factor rather than a direct causal factor.

For participants, the traumatic event itself was perceived to be less of a cause, rather, the way it made them feel and their ability (or inability) to deal with associated feelings was of greater significance. In addition to making the participants feel out of control, the majority of women reported difficulties in managing their emotions; consistent with previous quantitative research (e.g. Brockmeyer et al., 2014; Harrison et al., 2010). Gratz and Roemer (2004)'s conceptualisation of emotion regulation as multidimensional was reflected in the present findings. Lack of awareness or understanding of emotions was spoken about alongside difficulties in using effective strategies to manage emotions. The difficulty for participants in understanding as well as managing emotions also supports the findings of a relationship between alexithymia, and AN, BN (Cochrane et al., 1993; Marchiol et al., 2020; Schmidt et al., 1993) and BED (Pinaquy et al., 2003). In the present study, women across all diagnostic subtypes appeared to have difficulties in managing their emotions and used food– whether through restriction, binge eating, or purging– to block out emotions they felt unable to deal with. Similar to the present study, Kyriachou et al. (2009) determined, through interviews with patients with AN, clinicians and parents, that their participants with AN struggled to understand and cope with their own emotions and were over-sensitive to the emotions of others, causing difficulties in personal relationships and avoidance of social situations. Seeking social and emotional support is considered to be an effective coping strategy that the women in the present study appeared to lack prior to and during their ED, consistent with existing research (Bloks et al., 2004; Bloks et al., 2001). It is likely that if people are not sharing their problems or feelings with others then multiple stressors may accumulate to the point where they need to find an alternative outlet for this emotional need. These findings suggest that once using food has been established as a way of coping with trauma, it then becomes the main coping strategy for any form of stress or negative emotion.

Food was also used as a way to trigger positive emotions or a ‘high’. Research into emotion regulation generally focuses on negative affect, although during and immediately after purging has been described as a time of increased positive emotions (Mizes & Arbitell, 1991). Incorporating the use of EDs to purposefully generate positive emotions rather than to reduce or block negative ones provides an additional dimension to emotion regulation. Resorting to food to elicit a short-term mood increase, despite the long-term health consequences, may imply underlying low self-esteem. Levels of self-esteem have been found to predict happiness (Cheng & Furnham, 2003), and it is proposed that having low self-esteem can motivate actions to seek out positive feelings. This theory is evidenced by those participants who were driven by their desire to receive compliments and intensified their behaviours with the aim of receiving more. The majority of participants in the present study described having low self-esteem or low sense of self-worth. Quantitative research suggests self-esteem to be a moderator in the relationship between perfectionism and BN (Lilenfeld et al., 2000). Low contingent self-worth (dependant on appearance and relationship status) and maladaptive perfectionism have been found to interact to predict levels of disordered eating (Bardone-Cone et al., 2017). These findings suggest that low self-esteem and perfectionism may increase susceptibility to positive reinforcement, as compliments and a sense of achievement make them feel better about themselves.

In addition to feeling good, participants also described internalising compliments on their appearance as proof that their weight is something others pay attention to and as reinforcing the thin-ideal body type. This finding supports the complimentary weightism phenomenon, which proposes compliments reduce body satisfaction by causing women to feel judged on their appearance (Calogero et al., 2009). Reading compliments on the appearance of other women posted on images on social media has been found to increase body dissatisfaction (Tiggemann & Barbato, 2018), suggesting the complimentary weightism phenomenon, and the maintenance of EDs, extends to witnessing compliments made to other women. It is suggested that low self-esteem or self-worth, combined with clinical perfectionism, may increase sensitivity to the complimentary weightism phenomenon, as well as positive reinforcement, thus increasing the risk of developing an ED.

Judging themselves negatively in comparison to others is also indicative of low self-esteem (Tylka & Sabik, 2010). In addition to providing a platform for appearance-based compliments, imagery on social and traditional media was discussed by a small number of participants as increasing negative social comparisons. This could suggest the relationship between social media use and increased body concerns and disordered eating established in the literature (Tiggemann & Barbato, 2018; Tiggemann & Slater, 2013; Wilksch et al., 2020) may be linked to the process of making social comparisons. The tendency to engage in social comparison varies between individuals (Tiggemann & Zaccardo, 2015), with appearance-focused social comparisons found to be related to body dissatisfaction (Myers & Crowther, 2009). It has been found that this relationship was mediated by thin-ideal internalisation, a process which was exacerbated by a low self-concept, which the authors proposed was due to the need to use external sources to generate a sense of identity (Vartanian & Dey, 2013). Women with a high tendency for social comparison, particularly appearance-based, and a low self-concept and sense of self-worth appear to be more vulnerable to media imagery and peer exposure. Interventions aimed at reducing personal investment in societal ideals of appearance promoted through the media have been found to reduce body dissatisfaction, eating concerns, and perfectionism in adolescent girls (Wilksch et al., 2015). It is theorised that reducing investment in media portrayals of the thin ideal body type may reduce the impact of social comparisons on body dissatisfaction and EDs.

Participants described supressing their true self due to not feeling good enough for the affections of others and a fear of being abandoned. Fear of abandonment within EDs has been touched upon in the qualitative literature (Leavy et al., 2011). Research into the core beliefs of women with EDs, measured through levels of negative schemas, has found higher abandonment beliefs in women with AN, BN and BED than non-clinical comparison groups (Leung et al., 1999; Waller, 2003). There is however scope for further expansion into the influence of this factor. These insecurities influenced participants to behave in a way to try and please others, put the needs of others before their own, and hide their concerns or perceived weaknesses. Jack (1991) proposed that feminine social expectations put pressure on girls to conform to the stereotype that they should be nurturing and prioritise the needs of others. Conforming to these ideals then leads to self-silencing, in which self-expression of negative thoughts or feelings are supressed to avoid potential conflicts, and while the external portrayal of self to others is compliant, hostility, low self-esteem, and a loss of self builds within (Jack & Dill, 1992). Self-silencing has been found to be linked to disordered eating (Piran & Cormier, 2005) and it has been theorised that these feelings of hostility and supressed negative feelings are then displaced onto themselves and their bodies (Geller et al., 2010). It has further been suggested that self-silencing of emotions from a young age may lead to alexithymia, and therefore difficulties in understanding and processing emotions should be considered as more than a psychological impairment (Liang & West, 2011), further demonstrating the psychosocial context of EDs.

Difficulties in being one's true self may not only be associated with ineffective coping due to alexithymia, but also due to the reluctance to show any vulnerabilities to others. Participants spoke about how supressing their true self impacted on their ability to maintain close relationships, implying that they had fewer people who they felt they could confide in, which supports findings of loneliness as a contributing factor (Gulliksen et al., 2017) and a lack of seeking social and emotional support. A strong self-concept has been found to mediate the impact of stress on well-being (Ritchie et al., 2011), implying that identity struggles may impact on the ability to cope with stress and trauma. Weaver (2005) suggested putting the needs of others first may result in self-uncertainty, similar to the participants in the present study who described supressing their true self as causing a struggle to maintain a sense of identity. Supressing one's true self or having an uncertainty over one's identity is likely to be a source of additional stress as well as a barrier to building relationships. The psychological and social implications of identity suppression requires further research.

In summary, participants described a number of causes for their EDs, which may be related to an underlying low level of self-esteem. A drive to receive compliments and praise, which often began after weight loss, appeared to mark the start of disordered eating. Feeling unable to be their true self with people and problems with emotion regulation meant an inability to cope effectively when confronted with trauma or an accumulation of stress. A need for control appeared to increase the level of distress experienced during adverse events. Disordered eating behaviours then appeared to serve a function by increasing perceived levels of control or acting as a source of comfort, and thus became a coping strategy.

5.4.2 Maintenance

AN, BN and BED are all serious illnesses that bring with them many unique challenges for individuals to overcome to reach recovery. Firstly, recurring across different themes was the sense that participants perceived their EDs to have had a number of positive functions. AN and BN became established as ways to increase the perception of being in control and to feel a sense of achievement, addressing perfectionist tendencies. AN, BN and BED were all viewed as a way of coping with or controlling emotions. Perceiving their ED to be serving a positive purpose appeared to lead to denial of the illness, maintaining their behaviours over time until they became deeply ingrained. The thought of having to give up these ‘benefits’ resulted in ambivalence towards recovery, mirroring previous findings (Schmidt & Treasure, 2006; Williams & Reid, 2010). The importance of helping those with an ED to recognising this internal struggle is evident, as the realisation that the severity of the negative consequences outweighed any perceived benefits was central in aiding a genuine desire to recover.

Secondly, for some women, particularly with AN, they described their ED as being part of their identity and thus something that was extremely difficult to let go. This perception reflects the voices of women in several other qualitative studies (e.g. Leavy et al., 2011; Weaver, 2005). The implication is that self-uncertainty may be a risk factor for an ED becoming considered as part of one’s identity. Jenkins and Ogden (2012) referred to an anorexic voice that gains power over the rest of the mind. This notion of AN having its own voice was alluded to by some study participants who referred to their AN telling them to do things, and implies the ED was viewed as a separate entity rather than a part of them. For participants with BED, however, they spoke of feeling as though their mind had been taken over by an uncontrollable force and their sense of powerlessness was apparent in their stories.

Weaver (2005) reported that women hide their symptoms and the consequences of their AN as way of protecting their identity, however the concept of denial or not being aware of the severity of their illness was found to be a much stronger reason for not seeking help in the present study than trying to protect their identity. For the majority of women with BN and BED, they perceived their disorder to have been maintained for such a long period of time because they did not realise they were entitled to treatment. Consistent with existing research that suggests BED is not recognised as an illness by the public (O'Connor et al., 2016) and binge eating is perceived as a symptom of low self-esteem rather than a disorder (Mond & Hay, 2008), several participants did not realise what they were experiencing was not normal. Several other women, mainly with BN, did not feel able to ask for help due to not being underweight or were not taken seriously by a healthcare provider. This finding implies that despite efforts to emphasise that one does not have to be at a low weight to have an ED (Schaumberg et al., 2017), misconceptions of what a 'legitimate' ED looks like are still sometimes held by the public and professionals. A perceived lack of understanding and knowledge from professionals has been previously demonstrated (De Le Rie et al., 2006). Mitchison et al. (2017) stated that stereotypes of an ED and who experiences them are blinding health professionals from the full spectrum of disorders and restricting referrals. By not having their illness recognised or diagnosed participants felt unable to pursue further avenues for treatment, allowing the behaviours to continue, becoming more ingrained and more difficult to overcome.

To summarise, there can be a level of ambivalence experienced for women about their ED and the role it serves. The present study highlighted the importance of an effective response during the first help seeking interaction, to avoid behaviours becoming further ingrained. Misconceptions in the public sphere and among health professionals seem to be acting as a barrier to help seeking and specialised treatment.

5.4.3 Treatment

Ambivalence, denial and shame in those with EDs may act as barriers for general practitioners in making an informed assessment, especially in the limited time frames available (Surgenor & Maguire, 2013). Furthermore, health professionals have been reported as feeling inadequately trained, with limited funding and resources, to be able to respond effectively to EDs (Reid et al., 2010). There are therefore concerns regarding the effort women may have to expend to obtain a referral to the right treatment and the risk of feeling rejected or not good enough if they are turned away. Participants in the present study echoed these concerns, especially those with BN and BED who spoke of experiencing a greater level of stigma and believed there is less knowledge of these disorders.

Shame was experienced as a barrier to treatment by participants, particularly with BED and BN, stopping them from reaching out for help. Feelings of shame within EDs impeding help-seeking has been mentioned in the literature (Fox et al., 2017). Shame has been linked to feelings of inadequacy that they cannot cope with food (Rance et al., 2017a). It is proposed that a sense of shame may be linked to perfectionism and feeling that their ED is an imperfection that they should be ashamed of. Shame has also been associated with abuse (Kearney-Cooke & Striegel-Moore, 1994) and self-loathing (Gulliksen et al., 2017), suggesting that experiencing abuse and having low self-esteem may increase vulnerability to feeling shame. Kearney-Cooke and Striegel-Moore (1994) emphasised that clients in treatment are unlikely to openly discuss feeling ashamed and instead the therapist needs to pick up on signs. However, the potential benefits of addressing shame in the treatment of EDs appears to have been somewhat overlooked despite the apparent impact of carrying shame around and the relief felt when that burden is removed.

Linking back to the difficulties in being one’s true self, alleviating the fear of being an emotional burden to others was also considered to be important in treatment. As discussed, participants found it difficult to share their struggles with others, and this extends to therapists within treatment. Consistent with existing research (e.g. Button & Warren, 2001; Fox & Diab, 2015), the participants in the present study reported that it was important to establish trust and a good therapeutic relationship before they felt comfortable to be themselves and be open about their feelings. Previous research has suggested understanding and empathy to be a central part of establishing a good relationship (Pettersen & Rosenvinge, 2002; Rorty et al., 1993), however some participants were concerned about their emotions having consequences on the wellbeing of others. Although having a therapist who demonstrated an understanding of their situation and struggles was important, there appeared to be a level at which too much empathy may result in the client feeling like they are having an emotional impact on their therapist. There was a clear consensus that having a good relationship with their therapist was key to a positive outcome. Whilst some participants spoke of establishing a bond, others however emphasised the importance of professional boundaries in viewing their therapist as someone who would not be burdened by, or leave them as a result of, them sharing their struggles. Several participants were also concerned about letting people down and disappointing others, as a part of their fear of abandonment. This highlights the importance of having consistency and stability in their treatment team, and not reacting with disappointment or displeasure if patients experience a relapse. Furthermore, reflecting back on perceptions of control, participants were also more willing to engage in treatment in which they felt listened to and involved in decisions, supporting Eivors et al. (2003)’s conclusion that feeling a lack of control is central to dropout from treatment. Despite the necessity of a structured approach to nutritional rehabilitation in inpatient settings, participants’ perceptions in the present study, that mealtimes in treatment reflected a level of control over food and portion size that mirrored some ED behaviours, is noteworthy. If a need for control was an underlying psychological causal factor, then having the control of food taken away will likely be a particular struggle. Recognising the views of those with EDs may help treatment providers to ameliorate some levels of distress associated with certain aspects of treatment, such as supervised eating in inpatient settings.

Participants were clear that they perceived factors other than weight or food to be at the root of their illness, regardless of the diagnostic subtype. While weight restoration is an essential part of treatment for starvation, the majority of participants with AN believed that a greater focus needed to be given to their psychological health during treatment, a view often reported when conducting research from the patients' perspective (Beresin et al., 1989; Federici & Kaplan, 2008; Jenkins & Ogden, 2012; Rorty et al., 1993; Tierney, 2008). There was a general consensus among participants with AN in the present study that being required to reach a certain weight before beginning psychological treatment left them feeling like the psychological impact of weight gain was not being recognised or acknowledged, and thus the required level of support was not received. Previous research has found that cognitive impairment can be associated with being underweight and this impairment is normalised with weight restoration (Hatch et al., 2010), and treatment guidelines recommend psychological therapy to only begin once the cognitive impacts from starvation have improved (Hay et al., 2014). The participants in the present study however felt that this did not sufficiently recognise the level of distress women with AN experience when asked to eat or gain weight, which was perceived to be particularly important when the ED was their way of coping with distress. Learning alternative, healthy ways of coping with distress, and improving understanding of different emotions, was seen as helpful. Although difficulties in managing emotions constitutes part of the well-established cognitive-interpersonal maintenance model of AN and the associated MANTRA programme (Treasure & Schmidt, 2013), participants in the present study felt that they would have benefited from learning healthy coping strategies alongside weight restoration or receiving a greater level of support prior to learning new strategies, so as not to leave a gap in which they felt unable to cope.

Finally, there were mixed views around exposure to peers in treatment. Many women described a tendency to judge themselves negatively in comparison to others, and for some with AN this came with a risk of competing to be the most underweight in treatment and learning unhealthy behaviours from peers. It was considered helpful, however, to have support from peers who understood their experiences and could show that improvements were possible. Similar findings have been shown with group therapy and support groups (Beresin et al., 1989; Tierney, 2008). Participants with BED, on the other hand, focused on positive aspects of support groups, particularly not feeling alone and reducing shame.

Ultimately, the overlap between factors perceived to be important in treatment and the perceived causes of EDs is evident, demonstrating the importance in understanding the perceived underlying causes and psychological characteristics of the individual for effective treatment. For example, the role of control in the development of EDs also needs to be recognised in the way which treatment is delivered to ensure a sense of autonomy. Early abuse, low self-esteem and high levels of perfectionism may increase the likelihood of feeling shame and thus, strategies to address these factors may be helpful in treatment.

5.4.4 Recovery

Several participants, particularly with AN, had been through treatment multiple times before considering themselves to be recovered or on the journey towards recovery. Having a change in perspective was the key difference on entering treatment for their final time, and for continuing with improvements after discharge. As with treatment, the factors considered to be helpful for recovery were closely linked to the perceived causal and maintenance factors. Breaking down the belief systems in place that were maintaining their ED was a central part of recovery. An important part of this process was the realisation and acceptance that they had an illness, achieved through removing denial and increasing awareness of what behaviours are and are not normal. Realising the risk to their own mortality was a common trigger for changing the way they saw their ED, in line with Nilsson and Hagglof (2006). Comprehending the amount of control their ED had over them also helped to change their perspective, which is only partly in support of Patching and Lawler (2009), who described an internal battle to relinquish the idea that an even greater loss of control would be felt by stopping the ED behaviours. Participants in the present study, however, spoke of the realisation that they had been experiencing a false perception of control as a strong catalyst to recover. Struggles to relinquish the use of their ED for what they perceived to be a positive function focused upon the ED as a coping strategy rather than as a method of feeling control. The exception was for women with BED, for whom the role of control was experienced differently, as they struggled to free themselves from the control their ED had over them.

For most participants, removing the fear of being their true self aided recovery, as it allowed them to share their feelings with others and use social support as an alternative coping strategy. Other beneficial changes identified that assisted recovery were counteracting their perfectionism, accepting that recovery is a journey that may involve some setbacks, and learning not to feel guilty if they struggle at times. Challenging their thoughts was a central part of modifying the high expectations they placed on themselves, as well as increasing their confidence and self-esteem.

5.5 Limitations

There are several limitations of the present study that need to be acknowledged. In qualitative interviews the researcher is the data collection instrument, meaning they have a level of influence over the information collected. Firstly, aside from the questions on the interview schedule, the researcher decided on any follow-up questions and the areas they sought elaboration on. Despite reflecting on each interview before conducting the next, to identify any questions or responses that could have been approached differently, it is acknowledged that researcher subjectivities will have had some influence.

Furthermore, the position of the researcher themselves may also have had an impact on the amount of information the participants shared. The researcher in the present study, as someone who had not experienced an ED herself, would be considered to be an ‘outsider’. While attempts were made to reduce the impact this may have had, by not explicitly advising the participants of this fact, it is possible that they may have opened up more to someone they knew had shared some of their experiences. If the participants did view the researcher as an outsider, it may also have increased the likelihood that social desirability influenced some answers, if there were concerns that the researcher may not understand what they perceived to be an adverse belief. In addition to the risk associated with interviews conducted by an outsider, it also must be accepted that the short time frame may not have been sufficient to build the required level of rapport or trust required for participants to share complex feelings or discuss sensitive or traumatic topics.

As well as influencing the interview itself, researcher subjectivity is highly relevant during the analytical stage. As discussed in section 5.2.4.1, from a critical realist position, the findings from qualitative research are considered to be the researchers interpretations of the participants’ accounts and influenced by the researcher’s own experiences and knowledge. Despite not having lived experience of an ED, some elements of the participants’ stories resonated with the researcher, for example beliefs surrounding the role of social media as a platform for negative self-comparisons. A high level of empathy was also experienced in listening to some of the experiences, which could have impacted upon the ability to consider their account objectively. Reflexivity was an important process in identifying subjectivities, the awareness of which then aided in reducing the likelihood of any impact. Despite all of the attempts made to minimise the likelihood, the inevitability of a level of influence of the researcher’s own views and experiences must be recognised.

Although some participants explained how their perceptions had changed, the interviews captured their views at one distinct moment in time. Time constraints however meant multiple interviews with the same participants over a long term period was not possible. It must be recognised that perceptions can vary depending on circumstances such as mood, or over time. Based on research into the cognitive impact of EDs, and research that has demonstrated processes such as denial and poor insight in patients with EDs, it is likely that an individual’s perceptions may also change based on their recovery status. While all of the participants considered themselves to have improved at least to some extent, some still referred to themselves as having a significant ED. Although there were no clear differences among the views of participants based on their recovery status, it is possible that views, particularly around what was helpful in treatment, may change as they continue on their journey of recovery and look back on their experiences. The aim of this study was to gain a better understanding of the views of the participants, and while these views may change, the perceptions captured are still highly relevant as they may influence behaviours such as adherence to treatment.

5.6 Strengths

The qualitative methods employed in this study had a number of important strengths. Firstly, conducting semi-structured interviews allowed participants to provide a detailed account of their experiences and views, in their own words. The design of the interview schedule, consisting of (but not limited to) several open, broad questions, ensured that all of the topics pertaining to the research questions were discussed without restricting participants to certain subjects. Furthermore, despite the ability to conceptualise onset, maintenance, treatment and recovery as discrete constructs, the narratives participants provided highlighted the interconnectedness. The way in which this qualitative research enabled participants to explain how the roles of some factors changed throughout their journey, had multiple dimensions or were perceived to be interlinked with other influences demonstrated the importance of providing context and was a key strength of the study. The findings from this qualitative research also provided numerous insights that were complementary to the quantitative findings (the mixed methods integration is discussed in Chapter 6).

Taking a semi-structured approach also provided flexibility for the researcher to ask spontaneous follow-up questions and probe for further information on unexpected subjects that were of interest. Barriers to treatment, for example, were not asked about as part of the interview schedule as this was not within the scope of the research design, but it was a topic that the majority of participants discussed when asked about experiences of treatment. Had the interview schedule not allowed for this flexibility, then the impacts facing these barriers had on their perceptions of their ED would not have been explored. Furthermore, both the participant and the researcher were able to ask for clarifications, which minimised the risk of misunderstanding. Allowing a natural flow of conversation may have helped participants feel at ease, as they shared personal information that, for some, was accompanied by a high level of emotion.

Despite the limitations of approaching the research as an ‘outsider’, as discussed in the previous section, there are also some strengths. Firstly, there was minimal risk that the researcher would make assumptions based on their own experiences and thus fail to clarify or explore potentially novel insights further. Additionally, the thematic analysis was approached with a greater level of impartiality than from the perspective of someone with preconceived ideas, or strong opinions about the causes or treatment of their own ED or that of a loved one. Whilst it is acknowledged that some level of researcher subjectivity is inevitable, rigour was further ensured through multiple well established techniques (e.g. Lincoln & Guba, 1985), including peer consultation, as previously detailed in section 5.2.4.3; a further strength.

5.7 Implications

Whilst acknowledging the enormity of the task, the findings in this study demonstrate that continued efforts are needed to try to obtain a shift in the way that women are evaluated and portrayed within the media, including the number of stories published praising women for losing weight or complimenting women on their physical appearance. Messages promoted across the media and schools need to focus on healthy nutrition and healthy lifestyles. Recent changes in social media trends aiming to promote health and fitness, known as 'fitspiration', are still being linked to body dissatisfaction and disordered eating (Holland & Tiggemann, 2017; Prichard et al., 2020; Tiggemann & Zaccardo, 2015). Exposure to fitspiration posts has, however, been linked to lower levels of psychopathology than 'thinspiration' posts (Griffiths et al., 2018). It has also been found that viewing imagery focusing on body functionality rather than appearance failed to reduce negative impacts of social comparison on body image (Mulgrew & Tiggemann, 2018). The ways in which health messages are delivered therefore need careful consideration, including promoting the acceptance of different body types.

Several participants in the present sample highlighted the stigma they experienced surrounding being overweight with an ED, and emphasised the need to ensure people struggling are aware of the services that are available to them. This implies that continued work towards improving education and reducing the stigma associated with EDs is needed, which it is theorised will contribute towards removing some of the barriers that stand between those with EDs and treatment. The findings in this study also strengthen the claims by existing research that there is a lack of ED knowledge in some healthcare professionals, potentially due to insufficient training and resources (Reid et al., 2010). Healthcare professionals need to be able to recognise the signs of an ED and to know how to appropriately respond. In particular, there appears to be a need to improve referrals to specialised treatment for women with BED or to improve service provision in this area. Most importantly, ensuring that people feel their struggles are validated when they disclose for the first time is essential in reducing any shame or self-blame. Given the time it takes for those with an ED to accept they have an illness and seek help, it is also important that healthcare professionals take any concerns seriously and refer on for specialist ED treatment rather than trying to reassure and normalise symptoms that by that stage are likely to be entrenched.

The findings that women with an ED often have a fear of disappointing others and are sensitive to feedback may have important clinical implications. Perceived criticism is likely to be interpreted as failure, and several women in the sample described the difficulty in coping with feelings of guilt related to letting people down when they were told by their therapist that they had not made enough progress. Furthermore, whilst some participants described being driven to receive compliments, implying that positivity and encouragement may help to maintain a good therapeutic relationship, others struggled with the perceived pressure compliments brought. This finding is consistent with the proposal that people with low self-esteem struggle to accept compliments as they contradict self-theories, and this dissonance can elicit concerns over failure to meet that level of perceived expectation (Kille et al., 2017). This proposal, in combination with the present findings, suggests the use of compliments and praise in treatment needs to be carefully considered and tailored to the individual to avoid activating cognitive dissonance and to achieve positive outcomes.

The need to please people, and subsequent fear of being an emotional burden to others, may also have important clinical implications, particularly for the therapeutic relationship. The findings illustrate that therapists need to carefully determine the level of personal information shared to build rapport, so clients feel comfortable sharing, but ensure clients don't feel the relationship is too personal and fear their emotions will have a psychological impact. Although the relationship between client and therapist has been the topic of previous research (e.g. Graves et al., 2017), this aspect of establishing the right level of professional boundaries adds another dimension to theories of therapeutic alliance.

Finally, fear of abandonment in EDs is an under-researched area, yet the present study found it to be an important factor. The findings provide support for the use of schema therapy within ED treatment. Preliminary findings have suggested schema-focused therapies, including the early maladaptive schemas of abandonment and self-sacrifice, yield promising results across all ED diagnoses, but that further research is still required (McIntosh et al., 2016; Pugh, 2015). The conceptualisation of EDs stemming from a fear of abandonment, and the links this may have with other factors such as a drive for perfection, however, requires further research and development.

5.8 Conclusion

Through in-depth interviews with 18 women with lived experience of an ED, a wealth of data was collected, revealing each participant's personal experience. Despite their individual journeys, there were a number of similarities and patterns across their stories. Using thematic analysis, seven themes were identified: perceptions of being in or out of control, "people always compliment you for losing weight", difficulties in being one's true self, judging oneself negatively in comparison to others, emotion regulation, misconceptions of what a 'legitimate' eating disorder looks like, and change in perspective.

The participant narratives highlighted an underlying presence of psychological factors, which were often exacerbated by social interactions. The multitude of factors perceived to be involved in their EDs– including low self-esteem, perfectionism, a fear of abandonment, a need for control, difficulty coping with emotions, compliments on their body, comparing themselves to others, and experiences of trauma– and the variations in each woman's story, supports the prevailing view that AN, BN and BED are multifactorial with different causal and maintenance factors involved for different individuals. This study found a number of barriers that had to be overcome before being able to access treatment, for those with BN and BED in particular, meaning the ED was maintained for a prolonged period of time. Some participants described a lack of awareness of what was and was not normal behaviour with food, misconceptions about who can access treatment (particularly for people who were not underweight), and feelings of shame surrounding their behaviours. For some, once they had overcome personal barriers to ask for help, they encountered a second layer of obstacles in regards to health professionals, including insensitive responses, not taking them seriously, and not being referred for specialist treatment. When it is acknowledged that a large proportion of people who suffer from an ED do not receive treatment, increasing our understanding of these barriers so they can be removed is of utmost importance.

Participant views of what was important in treatment often reflected those factors perceived to be involved in the onset or maintenance of an ED, such as a tendency to compare themselves to their peers and the risk of unhealthy competition in a shared treatment environment. Furthermore, perceptions of control, a fear of abandonment, reactions to compliments, perfectionism and coping with emotions were factors that reoccurred throughout the different stages of their EDs. For instance, the theme of control was considered to be a causal factor (having a need to feel in control), a maintenance factor (AN and BN served the function of increasing perceptions of being in control), a factor that should be considered in treatment (allowing the client to be involved in decisions to ensure they do not feel treatment is out of their control) and important in recovery (realising the ED had taken over control as a catalyst). A fear of abandonment, for example, appeared to have contributed to self-uncertainty and self-sacrifice, (which were perceived to be involved in the onset of an ED), as well as a fear of being an emotional burden (maintaining the ED by acting as a barrier to seeking support and having implications for establishing the right therapeutic relationship for effective treatment). The benefit of researching causes, maintenance, treatment and recovery alongside each other, rather than in isolation, is therefore evident.

In conclusion, participant narratives highlighted the complexity and individual nature of EDs, and therefore the difficulties involved in creating an effective treatment model. Areas for further research remain, but the findings from this study aid in taking a step closer to understanding AN, BN, and BED.

CHAPTER SIX: A Narrative Integration of Quantitative and Qualitative Findings

6.1 Introduction

The core aim of this thesis was to establish a better understanding of the key factors involved in the onset and maintenance of EDs, and factors that are linked to effective treatment and recovery, from the perspective of a New Zealand sample of women with lived experience of an ED. The findings were further explored by comparing ED diagnostic subtypes and recovery status.

To address the aims and objectives, a mixed methods approach was taken. Conducting mixed methods research has a number of benefits, particularly for a complex topic like the one in question. Of particular importance here, the purpose was to triangulate findings and look for areas of commonality between the quantitative and qualitative results, therefore strengthening the validity of the findings from both methods through mutual corroboration (Bryman, 2006). Secondly, another key rationale for the use of mixed methods was complementarity; the opportunity to elaborate upon or enhance the results from one method by integrating with the result from the other method (Greene et al., 1989). In the present study, the findings from the participants' narratives provided further details to explain some of the patterns identified in the quantitative data. Finally, all methods of data collection have their own weaknesses, so by combining both quantitative and qualitative methods the goal was to offset some of the weaknesses of each method through the use of the other (Johnson & Onwuegbuzie, 2004). As discussed in Chapter 5, the quantitative survey limited the causal and recovery factors examined to those predetermined by the researcher and did not have scope for participants to elaborate or provide context for their responses. The qualitative interview, however, allowed participants to provide a nuanced account of their views and any factors they perceived as being relevant to their experience, without restriction. On the other hand, the qualitative research focused on a small number of personal narratives, whereas the quantitative study collected data from a wider range of participants which enabled for statistical comparison between groups.

In this PhD, a convergent design was used, meaning that both methods of data collection were conducted concurrently but separately, equally prioritised, and brought together for the final interpretation (Creswell & Plano-Clark, 2011). As explained in Chapter 2, the two methodologies employed in this thesis are in line with the two assumptions of critical realism; that people experience their own individual social realities, as well as underlying mechanisms that cause events in an independent reality.

This final chapter brings together and integrates the findings of the overall thesis. The weaving method of narrative integration (Fetters et al., 2013) was used to provide a comprehensive integration and discussion. The integrated findings are described here thematically and the results from both methods are presented together for each theme; weaving between quantitative and qualitative results in describing the findings that constitute each of the factors or concepts within each theme. Practical implications of the findings and directions for future research are then proposed.

6.2 Narrative Integration

The weaving method of narrative integration, as outlined by Fetters et al. (2013), makes the assumption that the key findings have already been identified through appropriate analysis and the focus in on bringing these together and presenting the integrated findings. The process of integration was conducted in two stages. Firstly, the findings from both methods were summarised and presented alongside each other; a process for which Fetters et al. recommended using a joint display. Thus, a table was used with a row for each theme and a column for each method, to visually display the quantitative findings beside the qualitative findings for each factor. This format helped to facilitate a comparison and interpretation incorporating both sets of findings. The summary of key findings from both methods can be found in Appendix K.

The second stage of the weaving integration is to present the integration by discussing each theme in turn, weaving between the quantitative findings and qualitative findings for each theme. Fetters et al. (2013) recommended using the format of the discussion by Classen et al. (2007) as a guide. Classen et al. (2007) presented each key finding in a separate section and structured each section by firstly stating the relevant quantitative findings, then the qualitative findings, then a comparison of those findings, and finally a brief discussion followed by any implications. The structure was used as a rough guide for the presentation of the narrative integration in this thesis.

Overall, there was a high level of convergence in the results from each method, with a coherent narrative evident that consisted of some diagnostic variation. A range of factors were perceived to be of importance in the four stages of an ED focused upon in this thesis: onset, maintenance, treatment and recovery. Several factors identified appeared to reoccur throughout the course of an ED, but the role these factors played varied at each stage. The role of emotion regulation, for example, illustrates this latter point; being unable to understand and express emotions was perceived as a causal factor, being able to use the ED to cope with emotions maintained ED behaviours, and learning alternative coping strategies in treatment was perceived to be beneficial for recovery. Understanding the ways in which causal factors may be related to the maintenance of an ED and the response to treatment also has implications that may contribute towards recovery. These links between the different stages demonstrate the importance of viewing the course of an ED holistically.

In addition to factors reoccurring across onset, maintenance and recovery from an ED, several different factors also appeared to be interlinked. Consistent with the psychosocial framework, in the research here underlying psychological factors were perceived to influence the response to social stimuli and environmental adversity. The interplay between psychological and social factors appeared to be particularly important. This interplay can be illustrated, for example, with perfectionism and compliments; for participants with high perfectionism, receiving compliments on weight loss was seen as an achievement and acted as positive reinforcement for disordered eating behaviours. Compliments were also internalised as pressure to live up to those expectations or be considered a failure, which has implications for the use of praise and criticism in treatment for clients with high perfectionism. Whilst each psychological or social factor identified could be considered in isolation, a more detailed understanding of the experience of an ED is gained by considering these factors in relation to one another.

6.2.1 Self-Esteem, Perfectionism, and the Impact on Compliments and Self-Comparisons

Low self-esteem was the most frequently endorsed cause of an ED in the online survey and an increase in self-esteem was perceived as central to recovery. The notion of low self-esteem or low self-worth also featured heavily in the thematic analysis, reoccurring within and having a role in shaping a number of the themes identified. The relationship between low self-esteem and EDs has been well established in previous quantitative studies (e.g. Brockmeyer et al., 2013; Daley et al., 2008; Dunkley & Grilo, 2007) and qualitative research (e.g. Granek, 2007; Gulliksen et al., 2017; Rossotto et al., 1996; Tozzi et al., 2002). Furthermore, in the qualitative study, having low self-esteem and a low sense of self-worth was identified as contributing to, or appeared to be linked to, additional perceived causal factors in AN, BN and BED, including a fear of abandonment (discussed later in this chapter) and perfectionism.

Many interview participants, across all diagnostic groups, described themselves as perfectionists or spoke of striving for perfection as a perceived cause of their ED. The resulting sense of achievement made them temporarily feel better about themselves, supporting the notion that perfectionist tendencies may stem from an attempt to seek validation (Flett et al., 2014). In corroboration with the qualitative findings, the survey results also showed that the majority of participants endorsed feeling a pressure to succeed and be perfect as a cause of their ED. While having high standards is often seen as positive, clinical perfectionism can have serious negative consequences (Shafran et al., 2010). Clinical perfectionism has been well established in the literature as being linked to both the onset and maintenance of EDs (e.g. Bardone-Cone et al., 2007; Egan et al., 2011; Holland et al., 2013; Wade et al., 2016), particularly when in combination with low self-esteem (Lilenfeld et al., 2000). Furthermore, maladaptive perfectionism has been found to be negatively correlated with self-esteem (Ashby & Rice, 2002). Low contingent self-worth (dependant on appearance and relationship status) and maladaptive perfectionism have been found to interact to predict levels of disordered eating (Bardone-Cone et al., 2017). Across both studies here, low self-esteem or self-worth and high perfectionism were frequently perceived causes of an ED. Considered alongside existing literature, the qualitative findings here suggest low self-worth may drive perfectionist behaviours as a means of validation.

In addition to a pressure to be perfect, participants in the quantitative study also endorsed “I felt pressure to be thin” as a cause of their ED. Interestingly, the qualitative findings diverged from the quantitative data here, with feeling pressure to look a certain way being perceived as a maintenance factor rather than a causal factor. This divergence could be due to the difficulty in differentiating between causal and maintenance factors using the quantitative survey method; demonstrating the benefit of also utilising qualitative methods in which participants could elaborate further. Several interview participants described how a perceived pressure to be thin often stemmed from receiving compliments on their appearance, especially an initial weight loss. Compliments made participants feel good to begin with, driving their dieting behaviours to receive more. Compliments on appearance, however, were also perceived as evidence that women are judged based on their appearance, consistent with the complimentary weightism phenomenon (Calogero et al., 2009). Objectification theory also posits that women are socialised to view themselves as objects that are evaluated based on their physical appearance (self-objectification), through the sexual objectification of the female body (Fredrickson & Roberts, 1997). Further, research found that appearance-based compliments increased immediate mood but also increased body shame for participants with high self-objectification, suggesting that any focus on the body, even complimentary, can have a negative impact on body satisfaction (Tiggemann & Boundy, 2008).

In the present study, the social factor of receiving compliments appeared to maintain disordered eating behaviours by both acting as a form of positive reinforcement and being internalised as pressure to maintain a thin appearance. Consistent with this proposal, previous research has reported that people with low self-esteem show greater affective reactions to positive feedback (Ilies et al., 2007), and internalise compliments as pressure to meet expectations that contradict their own self-theories (Kille et al., 2017). For people with perfectionism, the present research suggests that receiving a compliment may be perceived as an achievement and compliments on weight loss may promote the message that maintaining a low weight is one way to achieve perfection. Previous research has reported that reading compliments on the appearance of other women posted on social media increased body dissatisfaction (Tiggemann & Barbato, 2018), implying the impact of receiving an appearance-based compliment can extend to witnessing compliments paid to others. The qualitative findings, therefore, suggest compliments on appearance can act as a maintenance factor in EDs, particularly for women with low self-esteem and high perfectionism, who may be sensitive to self-objectification, positive reinforcement and cognitive dissonance. As discussed in Chapter 5, the findings about the role of compliments in EDs have implications for the use of praise within treatment.

Objectification has also been linked to social comparison, with women who are focused on their own appearance more likely to be attentive to the appearance of others and how they compare (Tylka & Sabik, 2010). In the qualitative study, it was identified that participants also had a tendency to compare themselves negatively to others, including peers and media imagery. Participants attributed social comparisons, particularly always judging themselves negatively, to both the onset and maintenance of their ED. The role of social comparison was not assessed in the quantitative study. Previous research has found a relationship between making appearance-focused comparisons, thin-ideal internalisation and increased body dissatisfaction (Myers & Crowther, 2009; Vartanian & Dey, 2013). Low self-esteem (Tylka & Sabik, 2010) and high perfectionism (Pokrajac-Bulian et al., 2008) have both been linked to an increased tendency for self-comparisons. In particular, Bailey and Ricciardelli (2010) determined that having self-worth that was contingent on reaching certain standards was associated with making upward comparisons (comparing themselves to people who they consider to be better or more attractive). Furthermore, perfectionism has been correlated with negative self-evaluations from social comparisons (Wyatt & Gilbert, 1998). In combination with existing literature, the present findings therefore suggest that low self-esteem and perfectionism may be underlying psychological factors that influence women to make social comparisons, particularly judging themselves negatively in comparison to others.

The tendency to make negative self-comparisons also has potential implications for treatment which vary according to the diagnostic group. In the qualitative study, several participants with AN perceived peer exposure during inpatient treatment as harmful to their recovery, due to their tendency to compare themselves to others and being in a competitive environment fuelled by perfectionism. Alternatively, women with BED felt they benefited from a shared peer environment as it helped them to realise they were not alone. Similarly, in the online survey, participants with BED more frequently endorsed support groups and organisations as being helpful in recovery than participants with AN and BN. Notwithstanding the probable service provision difference (where less individual treatment is available to those with BED), the qualitative findings supported and elaborated upon the survey results, indicating diagnostic differences in the perceived helpfulness of group support may be due to different impacts of peer exposure. Findings from the present research support previous observations that shared peer environments for AN can, at times, foster competition and bad habits (Colton & Pistrang, 2004; Offord et al., 2006) but can help women with BED feel less isolated (Higgins Neyland & Bardone-Cone, 2019). Thus the tendency to make negative social comparisons may be an isolating experience for women with BED that benefits from peer support, but may foster competition in AN.

6.2.2 Fear of Abandonment and Suppression of True Self

A low sense of self-worth also appeared to underpin a fear of abandonment and a subsequent struggle to show their true self to others. Supressing their true self for fear of being abandoned was described as impacting upon relationships with others, which had implications for the onset, maintenance and treatment of AN, BN and BED.

Many participants in the qualitative study described a fear of abandonment being a causal factor for their ED, which appeared to stem from not feeling good enough for the affections of others. For these participants their fears resulted in hiding their true selves, putting the needs of others before their own in an attempt to please people, and neglecting their own self-care; behaviours that caused further distress they then had to cope with. Although maladaptive schemas, including abandonment and self-sacrifice, have been found to be associated with EDs (Jones et al., 2007; Waller, 2003), fear of abandonment in EDs has only briefly been touched upon in the qualitative literature (Leavy et al., 2011). The role many participants, across all diagnostic groups, perceived their abandonment fears to play in the onset, maintenance and treatment of their ED only became evident through the qualitative methods. These findings provide a valuable contribution to the limited literature on this topic.

As a result of their fear of being abandoned and need to please people, many interview participants also described how they supressed, rather than shared, any struggles as they feared letting people down and being an emotional burden. This qualitative finding may also be reflected in the quantitative study, as almost two thirds of participants in the online survey endorsed having no-one to share their innermost thoughts and feelings with as being a causal factor in their ED. Given this finding, a fearful avoidant adult attachment style, characterised as a desire for intimacy but avoidance of close relationships through fear of rejection and viewing the self as unworthy (Bartholomew, 1990), may be an influence in the onset of EDs. Together, these findings also indicate that the participants felt unable to access social and emotional support as a coping mechanism, consistent with findings by Bloks et al. (2001), and felt unable to ask for help, maintaining their ED. The role of lacking social support as a coping strategy in the maintenance of an ED may support the teaching of healthy coping strategies in treatment.

Furthermore, the qualitative findings indicated that concerns over abandonment and being an emotional burden were relevant to relationships with medical professionals and therapists in treatment, as well as participants' social network. Establishing a strong therapeutic relationship was important, with building trust a key component before participants felt able to show their true self to their therapist. Of note, maintaining professional boundaries and the right level of empathy was also important to reduce concerns about their story and struggles impacting on the wellbeing of the therapist. Unexpectedly, the quantitative results diverged slightly from the qualitative finding here, with only half of the survey participants endorsing “good relationship with treatment team” as a recovery factor. Although the importance to clients of having a good therapeutic relationship has been previously documented (e.g. Button & Warren, 2001; Fox & Diab, 2015), Graves et al. (2017) concluded that additional factors such as the type of treatment may mediate the relationship between the level of therapeutic alliance and treatment outcome. Additionally, a good therapeutic relationship has been linked to other factors established within the treatment efficacy literature, such as self-motivation (Geller et al., 2011).

6.2.3 Control, Emotion Regulation and the Impact of Trauma

The role of control throughout the course of an ED was established using both methods, with some important diagnostic variations evident. Participants with AN and BN perceived their ED as helping them feel a sense of control in their life, which they believed caused (and in the qualitative data, maintained) their disorder. In the quantitative analyses, participants with BED were significantly less likely to endorse this as a causal factor. Considering this quantitative data alone, this might suggest that control plays a lesser role in BED than in AN and BN. It was identified in the qualitative study, however, that participants across all diagnostic groups spoke of having a need to feel in control, similar to the findings of Surgenor et al. (2003).

The qualitative findings further suggested that the participants with AN and BN regained the perception of having control by restricting what food entered, or using compensatory behaviours to control what food remained, in their body (consistent with Slade, 1982). In contrast, women with BED spoke of feeling out of control of their binge eating and that this caused additional distress. These women then responded to their distress by using their ED to self soothe, consistent with the theory proposed by Carson (2016) and linking to emotion regulation. Consequently, these results suggest the role of control is complex, and the desire to feel in control is important in treatment for BED as well as AN and BN. Women with BED appeared to be trapped within a cycle in which food acted as both a source of comfort and distress, mirroring the voices of participants in previous research into the experiences of living with obesity (Rand et al., 2017). Despite the diagnostic differences, distress at feeling out of control was a consistent theme across all EDs, which also has implications when delivering treatment (which are discussed in section 6.3).

Using the ED as a means to self-soothe or to cope with the negative emotions resulting from feeling out of control also implies difficulties in coping with negative emotions in healthy ways. The subject of emotion regulation featured heavily in both studies, spanning the onset, maintenance, treatment and recovery of EDs. In the online survey, the second most frequently endorsed potential cause of an ED was participants' belief that it helped them cope when feeling stress or other negative emotions. Correspondingly, nearly two thirds of participants endorsed being able to express and cope with negative emotions in alternative ways as a recovery factor. These findings were reflected in the narratives of interview participants, constituting the theme 'emotion regulation'. These participants explained how they struggled to understand and cope with emotions, and how their relationship with food became imbedded as a coping strategy, maintaining these ED behaviours. Participants with AN, BN and BED described using food to feel in control, trigger feelings of comfort or distract from negative emotions. Findings from both methods therefore converged in indicating that women with emotion regulation difficulties were at risk of developing an ED as a way of coping, consistent with existing research (e.g. Brockmeyer et al., 2014; Harrison et al., 2010). Teaching healthy alternative coping strategies, as is done in therapies like CBT-Eb (Fairburn et al., 2009) and MANTRA (Schmidt et al., 2014), is likely to help to alleviate these difficulties.

Both a desire to feel in control and emotion regulation difficulties appeared to impact upon the response to experiencing trauma. In the quantitative study, just over half of the survey participants endorsed a traumatic event or experience as being a cause of their ED; lower than expected. This proportion is similar to estimates of trauma prevalence in the New Zealand population (Flett et al., 2002), rather than higher than the general population. This finding may, however, reflect the proportion of participants who perceived trauma to be a cause rather than the prevalence of trauma in the sample. The majority of participants in the qualitative study spoke of at least one form of distressing event or experience, although not all saw the experience as a direct cause of their ED. Instead, these participants described the difficulties they had in coping with the emotions, triggered by the experience, as contributing to their ED. Furthermore, experiencing trauma often left participants feeling powerless and intensified the need to regain a sense of control. Kearney-Cooke and Striegel-Moore (1994) concluded from their review that trauma often feels uncontrollable and by controlling food and appearance, amongst other things, it can increase feelings of control and competence. Using the ED as a way to cope when faced with distress, or to regain a perceived loss of control, implied the ED was serving an affect regulation function. Participants' narratives in the qualitative study indicated that, across all diagnostic groups, their ED was perceived to have a positive function and that this was a strong maintenance factor.

Several interview participants stated that realising the negative impacts of their ED outweighed the perceived benefits was important for their recovery. In the quantitative analysis it was evident that participants were less likely to be in the recovered category if they perceived their ED helping them to cope was a causal factor. The findings from both methods therefore converged in indicating that relinquishing the idea that an ED serves a positive function was an important step in being able to move towards recovery for all diagnostic subtypes. Previous qualitative research with participants who stated they wished to maintain their AN found that while they recognised AN as a disease that was negatively impacting on their health and wellbeing, they strongly valued the perceived functional role it served (Williams & Reid, 2010). Targeting the valued role of the ED is part of some treatments for AN e.g. MANTRA (Schmidt et al., 2014), and, as discussed elsewhere, the present findings confirm the importance of including a focus on relinquishing the positive function of the ED in treatment for BN and BED, as well as AN.

6.2.4 Barriers to Treatment and Recovery

In the quantitative study it was evident that participants with BED and BN were more likely than participants with AN to endorse being bullied or teased about their weight or appearance as a cause of their ED. In contrast, there were no clear diagnostic differences evident in the qualitative study, and bullying was not a frequently perceived cause. Some interview participants with BED and BN did, however, describe feeling a stigma attached to being overweight that fostered feelings of shame. These feelings of shame and a fear of encountering further stigma acted as a barrier to help seeking. Previous research has identified a high level of stigma towards EDs within society and some health professionals (Ali et al., 2017), particularly for BED, which has been viewed as a self-discipline rather than medical issue (O’Connor et al., 2016; Reas, 2017). Previous research has also suggested a high level of stigma towards BN, particularly for those who are overweight (Galbraith et al., 2019). Fear of the stigma, lack of awareness of treatment availability, and self-shame were the most prominent barriers to treatment seeking in Hepworth and Paxton (2007)’s study with a sample of participants with BN and BED. Goss and Gilbert (2002) have proposed that the role of shame may be greater in BN and BED, as people with AN can tend to feel a sense of pride in their ability to restrict. When considered alongside social pressures surrounding being overweight, such as obesity stigma (Greenberg et al., 2003) and fat shaming (Chou et al., 2014; Hussin et al., 2011), it appears that stigma, shame and fear of further judgement can be a strong barrier to help seeking that is particularly relevant for women with BN and BED.

When asked about their experiences of treatment, the majority of interview participants, particularly those with BED and BN, began by recounting the barriers they had experienced when attempting to access treatment. This barriers aspect, in the journey from onset to recovery from an ED, would have been overlooked if conducting the quantitative study alone as it was not anticipated to have been as ubiquitous when designing the survey. In addition to shame, other barriers described by participants included not realising they had an illness, not realising they were entitled to treatment, and medical professionals not recognising signs or not taking concerns seriously. These findings align with existing research which has proposed that barriers to treatment are underpinned by a lack of awareness and understanding of the different types of EDs within society (O'Connor et al., 2016) and limited resources and training for the healthcare sector (Reid et al., 2010; Surgenor & Maguire, 2013). This parallel between the findings in the present study and previous research implies that the participants' perceptions of stigma and a lack of knowledge of EDs are a true reflection of the state of understanding of EDs in society, which has implications for the improving access to treatment (see section 6.4).

In the qualitative study, several women explained that understanding the reasons behind their illness helped to remove shame and self-blame, which was described as lifting a burden and reducing self-criticism. In both studies here, participants perceived it to be very important to tackle underlying psychological causes in the treatment of EDs. Numerous participants spoke of ways in which alleviating the impacts of perceived psychological causal factors, including perfectionism and difficulties in coping with emotions, was beneficial for recovery. In the quantitative study it was found that tackling underlying causes was the second highest ranked recovery factor. However, there were no strong correlations between endorsement of the causal factors of self-esteem, control and coping with emotions, and endorsement of addressing those factors in recovery. It could therefore be inferred that, although clients benefit from having a greater understanding of the reasons behind their ED, treatments that focus on breaking down factors maintaining the ED may have a greater impact on recovery.

The findings in the present study, that low self-esteem, perfectionism and emotion regulation were prominent factors throughout EDs, are consistent with Fairburn et al. (2003a)'s transdiagnostic theory of the maintenance of EDs. This theory incorporated an over-evaluation of weight and shape, clinical perfectionism, low self-esteem, mood intolerance and interpersonal difficulties, and was the basis for CBT-Eb. There is abundant evidence for the efficacy of CBT for the treatment of EDs; CBT-E (e.g. Linardon et al., 2017; Waller, 2016a). As discussed earlier in this thesis, CBT-Eb was found to be more effective than CBT-E for those in which the factors were deemed to be present but less effective for individuals for whom the targeted maintenance factors were not relevant (Fairburn et al., 2009). This finding demonstrates that not everyone requires the same level of complexity in treatment. In the transdiagnostic theory it is proposed that the same core psychopathology underpins all EDs (Fairburn et al., 2003a). While the present project established a number of similarities between AN and BN, and across EDs as a whole, there were also some areas (e.g. weight stigma and bullying) in which BN was more closely aligned with BED. Furthermore, individual differences among participants within the same diagnostic group were evident. Due to the heterogeneity of each ED, is proposed that treatment needs to incorporate what each individual thinks is important to maximise engagement, and provide the relevant level of complexity to address the key maintenance factors present for each individual. In addition to the core elements of treatment, therefore, flexible treatment packages are likely to offer the most effective option.

Another factor that was identified as important for recovery was self-motivation; although this was an area of divergence between study methodologies. In the quantitative data, self-motivation was the most frequently endorsed recovery factor and was the strongest predictor of being in the recovered category. However, self-motivation was not emphasised by the interview participants. When asked about important factors for effective treatment and recovery, interview participants mainly discussed external factors rather than considering their own attributes to be an influence, possibly representing an external locus of control or lack of sense of agency. When prompted however, by asking about this option specifically on the survey, self-motivation was identified as a key recovery factor. As such, the research here supports the notion that self-motivation does appear to be an important aspect for recovery.

As discussed in Chapter 4, trials using motivational interviewing (Knowles et al., 2013) and motivational enhancement therapy (Treasure et al., 1999) failed to demonstrated their worth over other types of treatment. A study into readiness and motivation therapy found readiness to change did not appear to improve but levels of ambivalence towards their ED did reduce (Geller et al., 2011). The inclusion of a strong therapeutic alliance was concluded to have contributed to the improvements seen in both the motivational enhancement therapy and the readiness and motivation therapy (Geller et al., 2011; Treasure et al., 1999). Geller and Dunn (2011) proposed integrating motivational interviewing into CBT, to build a strong therapeutic alliance through gaining an understanding of the client's feelings towards change and mutually agreeing treatment goals dependent on readiness. The findings of the present study support those latter studies in noting the importance of attention to the therapeutic relationship and attending to client motivation and perspectives. The present findings are also consistent with the self-determination theory (Ryan & Deci, 2000), which states that autonomy, connectedness and competence increase motivation. Considered together, this indicates that establishing a good therapeutic relationship, ensuring the client feels a sense of control over their treatment and increasing self-esteem is likely to increase self-motivation and thus the likelihood to recover. Further research is required to explore these ideas.

6.2.5 A Psychosocial Model

During the process of this narrative integration, several factors were identified that were particularly important throughout the course of an ED, contributing to onset, maintenance, treatment and recovery. To further aid in explaining the integrated findings, a psychosocial model was developed (see Figure 2). The model illustrates each of the psychological causal factors identified, alongside the social factors they were perceived to have influenced responses to. Considered together, these psychosocial processes were perceived to contribute to the onset of an ED. With reference to Figure 2, flowing from left to right across the different stages of an ED, the model illustrates how these psychosocial causal factors were linked to the maintenance of an ED, had implications for treatment, and influenced recovery. The existence of barriers that interrupt the ability to access treatment and achieve recovery are also represented in the model in Figure 2. Links between causal factors are also demonstrated, with some of these links occurring between themes. Further, findings from the quantitative study only, the qualitative study only, and where the findings from both methods converged are highlighted in the model.

Six key psychological factors were identified that appeared to increase the likelihood of developing and maintaining an ED, and had implications for treatment. Firstly, *low self-esteem or low self-worth* was linked to *high perfectionism*, both of which were factors that increased the tendency to make negative self-comparisons; a factor considered to contribute to onset and maintenance of an ED. Low self-esteem, low self-worth and high perfectionism also appear to influence the response to receiving compliments; compliments can act as positive reinforcement for initial weight loss behaviours and as a pressure to maintain a lower weight. The tendency to compare to others has implications for the management of peer exposure in treatment and the influence of compliments has implications for the use of praise.

Low self-esteem and low self-worth were also connected to a *fear of abandonment*, and acting as a *people pleaser* to try and appease these feelings. Fear of abandonment influenced behaviours in social situations, influencing the suppression of one's true self and needs; factors perceived to contribute to the onset of an ED. The impact of these psychological aspects on relationships meant the ability to use a social support network as a coping strategy was lacking, which contributed to the maintenance of the ED. The difficulty in accessing social support demonstrated the importance of establishing a strong therapeutic relationship, as well as focusing on skills to improve interpersonal relationships.

A desire to feel in *control* and difficulties in *regulating emotions* were also considered to be psychological causal factors, both of which were further exacerbated when faced with trauma or distress. The ED then became embedded as a strategy to cope with negative emotions and feelings of being out of control. The perception that the ED served a positive function was a strong maintenance factor, a perspective that was seen as important to change for recovery to occur.

The importance of having self-motivation for recovery was also demonstrated, highlighting the need to address motivation in treatment. Finally, low self-esteem, high perfectionism, a fear of abandonment, being a people pleaser, control and emotion regulation difficulties contributed, albeit in different ways, to the maintenance of an ED. The implications of this are that concentrating on addressing these factors in treatment is likely to be important for recovery.

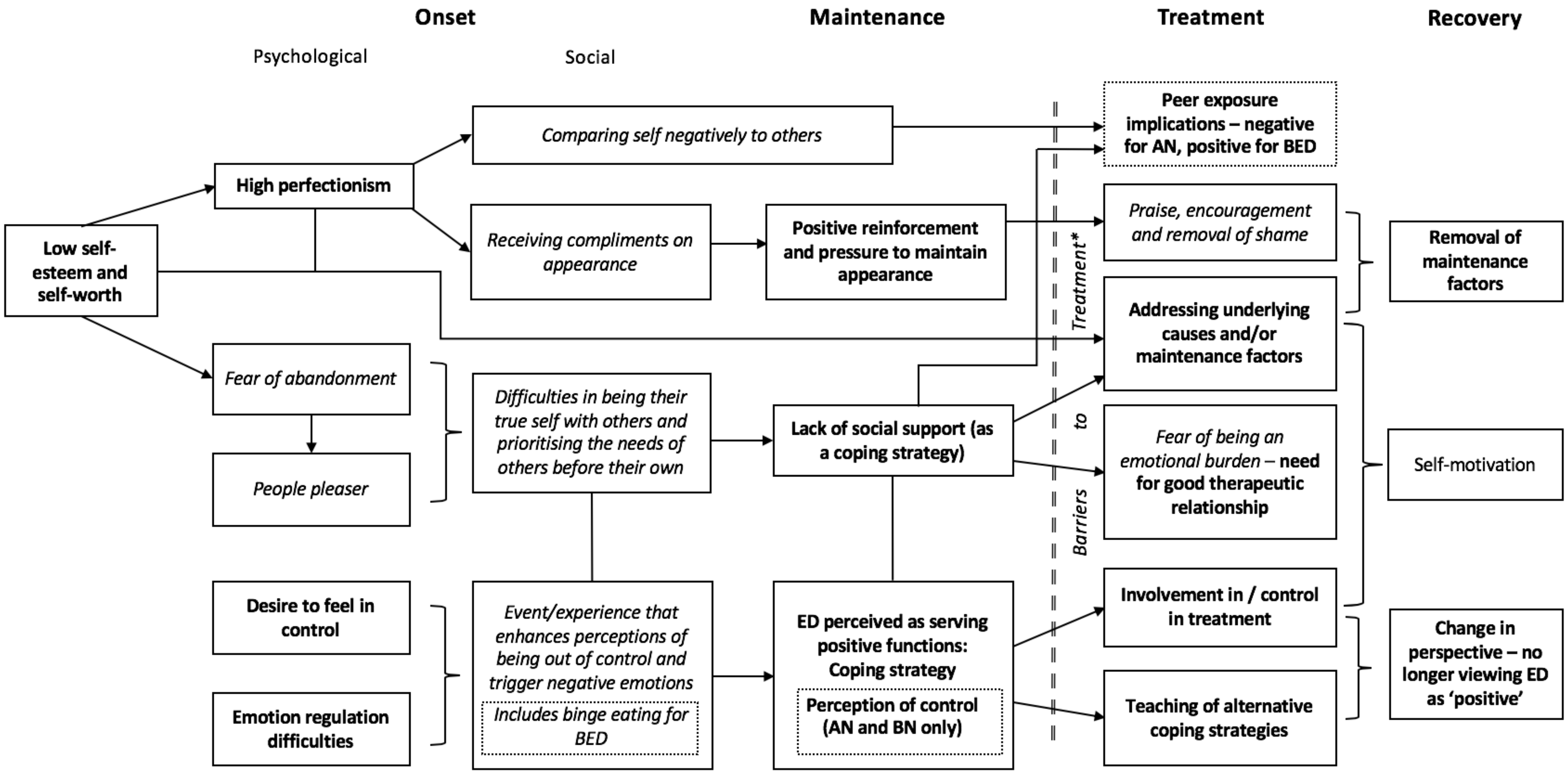

Figure 2: Psychosocial model of the key factors identified as contributing to the onset, maintenance, treatment and recovery of EDs, from the perspective of women with lived experience. Arrows illustrate the links between factors, particularly psychological factors and social stimuli, and the implications of these psychosocial factors at each stage.

Notes: Diagnostic differences are shown using a dotted line. Findings from a convergence of both methods are in bold, findings from qualitative data are in italics and findings from quantitative data are in standard text. * = Barriers to treatment.

6.2.6 Summary

In summary, this thesis identified a number of psychosocial factors that featured throughout an ED, from the perceptive of participants with lived experience. The findings demonstrate that EDs are influenced by a range of different factors, supporting multifactorial models of EDs. The integrated findings from the quantitative and qualitative studies were incorporated into a psychosocial model illustrating the key factors identified, and the influence at each stage of the ED (onset, maintenance, treatment and recovery). Several diagnostic differences are also highlighted in the model, as the findings demonstrated the importance of not theorising that all factors of importance in EDs are transdiagnostic. These findings have a number of implications for the prevention and treatment of EDs, as well as future research, which are discussed below.

There was a high level of coherence when integrating the qualitative and quantitative findings, with the 'fit' of the integration being a mixture of confirmation and expansion (Fetters et al., 2013). The two methods provided similar results, supporting the conclusions drawn from each method and, in some cases, the two methods together expanded the level of insight. For example, with the role of control, the qualitative data provided a greater level of detail which allowed a more nuanced understanding of the quantitative analyses. The main area of divergence was the amount of emphasis placed on the importance of self-motivation for recovery. The inductive nature of the qualitative study allowed for additional factors to be explored that were not examined in the quantitative study, particularly barriers experienced when seeking treatment. Overall, the most findings were corroborated through both methods.

6.3 Strengths and Limitations of the Mixed Methods Design

Using a mixed methods approach was a key strength of this research project for a number of reasons, which have been previously discussed throughout this thesis but are recapped here. Firstly, some of the weaknesses of one method, such as the restriction of the quantitative survey to predefined factors, were able to be offset through the use of the other method; in this case asking broad open-ended interview questions. Next, the convergent design, in which both studies were conducted concurrently, enabled the triangulation of findings from the two separate studies. Triangulation of the findings from each method strengthened the conclusions drawn as there was a high level of convergence. Finally, in the mixed methods integration, the findings from the qualitative study provided an in-depth account that elaborated upon some of the quantitative results, enhancing the overall findings and aiding a greater understanding of a complex topic.

Although the concurrent mixed methods design utilised had a number of strengths, it also had limitations. Conducting each study separately and concurrently meant some topics were not explored in both studies, restricting the ability to corroborate those findings or to seek further explanation through the alternative method. An alternative approach would have been to use a sequential design, in which the qualitative study was conducted first, and the findings then used to inform the survey measures. Taking this approach may have provided further findings relating to certain topics that were only identified through the qualitative study, such as fear of abandonment, fear of being an emotional burden, and different barriers to treatment. These factors could then been quantitatively analysed to determine any significant differences between diagnostic groups. Alternatively, conducting the quantitative study first would have enabled clarifications on reasonings behind survey responses to be sought from participants in the following qualitative study, such as asking participants for their views on the role of self-motivation. In the time constraints of the present thesis, however, a sequential design would have reduced the recruitment period for each study, potentially adversely impacting on the sample size. The concurrent design used maximised the data collection periods for each study and triangulation of findings is strengthened by conducting each study independently.

6.4 Implications

The findings from this project have a number of implications for the prevention of EDs and clinical implications for treatment. Overall, the research demonstrated that EDs are complex illnesses, with a range of psychological and social causal factors that also need to be considered during treatment, contributing to the psychosocial theories of EDs. The links established between perceived causal factors and important elements of treatment, for example the impact of compliments and the use of praise in treatment, also have implications for the importance of considering EDs holistically rather than taking a siloed approach and theorising each aspect of an ED or factor involved in isolation.

As mentioned in Chapter 5, acceptance of different body types promoted through media imagery, and a reduction in stories published by the media that compliment women for weight loss, are recommended to remove the constant focus on a thin-ideal body type. In recognising the difficulty to sustain any lasting influence over media messaging, it may be of benefit to consider implementing media literacy interventions in schools, prior to the high risk age for developing an ED. Delivery of a media literacy programme, Media Smart (targeting media internalisation, investment in societal ideals and resisting social pressures), has demonstrated reductions in shape and weight concern, body dissatisfaction and dieting (Wilksch & Wade, 2009; Wilksch et al., 2015). Results from the present study support the importance of these types of programmes, as well as education about different body types, to reduce the impact of the internalisation of societal ideals, potentially acting as a prevention strategies for the development of EDs.

It is also important to continue to educate the public about the different types of EDs beyond AN and to break the stigma attached to EDs, such as the work by The Academy of Eating Disorders who have disseminated documentation globally dispelling myths about EDs (Schaumberg et al., 2017). Working towards improving the knowledge of the general public may also help the family and friends of people who may be in the early stages of an ED to recognise the signs, know how to respond and know the best way to offer support. As discussed in Chapter 5, the findings in this research, along with existing research (e.g. Ali et al., 2017; O'Connor et al., 2016), demonstrate the importance of gaining a better understanding of how factors such as stigma and a lack of understanding of EDs (in health professionals as well as the public) are acting as a barrier to treatment access. The present findings suggest that further research is required to better understand how to break down these barriers. Considering the low proportion of people with EDs estimated to receive treatment, it is crucial to make access to treatment as easy as possible.

Within treatment, encouraging a sense of autonomy is important in addressing the need to feel a sense of control for people with an ED. Building on the findings of Vandereycken and Vansteenkiste (2009), that dropout rates reduced when inpatients were given a choice on entering treatment, findings in the present study highlight the importance of listening to client views and enabling their involvement in decisions whenever possible. Furthermore, using the self-determination theory (Ryan & Deci, 2000), therapists applying an autonomy-supportive style to their treatment of depression were found to increase autonomous motivation and generate more positive outcomes (Zuroff et al., 2007). Along with incorporating motivational enhancement techniques into treatment, as discussed in Chapter 4, the present findings support building autonomy within ED treatment to improve efficacy.

The integrated findings here also support the use of treatment programmes that incorporate optional modules designed to increase self-esteem, reduce perfectionism, and aid emotion regulation (such as CBT-Eb and MANTRA). Focusing directly on maintenance factors appears to assist recovery, with the caveat that maintenance factors vary among individuals and thus require personalised treatment plans. Regardless of ED diagnosis, participants perceived tackling the underlying causes of their ED to be of importance. It is therefore recommended, even if treatment is tailored to focus on maintenance factors, that the underlying causes identified by the client are also taken into consideration for a number of reasons. Firstly, understanding the reasons behind their illness may remove self-blame and shame. Next, the client's perception of the causes of their ED may impact on their views of treatment credibility, which could impact on adherence (Petrie et al., 2008) and/or dropout (Jordan et al., 2017). Finally, acknowledging the client's views of causes, maintenance and treatment decisions may also help them feel involved in treatment, similar to the implications surrounding autonomy, and therefore engage more effectively.

The integrated findings surrounding emotion regulation provide support to the body of literature that states teaching healthy coping strategies should be included within ED treatment (e.g. Fairburn et al., 2009; Schmidt et al., 2014). Within inpatient treatment for AN, although teaching healthy coping strategies is often already incorporated, participants in the present qualitative study felt that this needed to begin immediately on admission to provide sufficient psychological support for the very stressful but necessary focus on weight restoration. Furthermore, although preparation for life post-discharge is likely to be present already in some inpatient programmes, participants with AN in the present sample also stated that this needed a greater focus, including less structured mealtimes. Although it is a recognised issue, the participants' narratives also emphasised the need for greater consideration to be given to minimising the negative consequences of peer exposure during the early stages of inpatient treatment for AN. It appears that being in an environment with peers who are also struggling can foster an unhealthy competitive environment and so this needs close monitoring. Of note, being exposed to people who were further along the recovery journey was considered helpful, as it demonstrated that recovery is possible. It is therefore suggested that incorporating the sharing of stories from clients who have recovered may be a beneficial element to treatment of AN, BN and BED.

Additionally, as discussed in Chapter 4, diagnostic differences found in this research imply that there should be some variation in treatment based on ED diagnosis. These differences include programmes for women with BED having a greater focus on food and body image, and group therapy and peer support being recommended for BED, alongside individualised treatment plans. The diagnostic specific findings suggest that EDs should not be considered under one transdiagnostic theory of onset and maintenance. It needs to be acknowledged that there are clear differences in the experiences of women with AN, BN and BED, and thus, research needs to distinguish between these groups before generalising or applying theory across all diagnoses.

One area in which diagnostic differences were identified was in the role of control. For women with BED, it appears that they struggle with feeling out of control, similar to AN and BN, but this feeling is intensified by their ED rather than relieved. The only way they feel they can then cope with this distress is to use their BED to make themselves feel better. Whilst control is a well-established concept in AN (Slade, 1982; Surgenor et al., 2003; Surgenor et al., 2002), the cyclic notion of control for women with BED proposed here is under-researched and may be an important contribution to the theory underpinning the maintenance of BED.

6.5 Future Research

There are a number of avenues proposed for future research based on the present project. It would be of interest to extend the scope of the present research to include male and gender diverse participants, to gain an insight into the perspectives and experiences of these under-researched groups, which could have implications for treatment. The scope could also be extended to explore any differences between participants with a single ED diagnosis and those with multiple diagnoses. The project could also be replicated in other countries outside of New Zealand. Furthermore, utilising a longitudinal design in future research, in which participants complete the quantitative survey and qualitative interview at multiple follow-up intervals, could investigate fluctuations in perceptions over time. In particular, this would allow any changes in an individual's perception related to their stage of recovery to be explored.

Based on the findings in this project, there were several factors identified that warrant further examination. The concept of a fear of abandonment has only been touched upon in the ED literature to date. The present study found this to be an important causal factor that also appeared to influence processes such as identity suppression and self-sacrifice, which had implications for maintenance and treatment. Further research into the psychological and social impacts of a fear of abandonment, how these impacts may relate to the etiology of EDs, and implications for treatment (such as the therapeutic relationship and the use of schema therapy) may be beneficial. Additionally, further research into identity suppression in EDs, and the possible link to a loss of self-identity and regaining that sense of identity from an ED may be of interest. As discussed, AN being considered as part of one's identity has featured within existing literature, however the research in this area is lacking for BN and BED.

Results from the present study indicated self-motivation to be an important factor in recovery, however in terms of improving treatment outcomes, evidence for the effectiveness of a therapy to enhance self-motivation and readiness for change appears contradictory. Studies in which there was no significant difference found between the control and test groups still implied there may be some benefits. Future research is needed to increase our understanding of the processes involved in increasing self-motivation to change for people with an ED so that this can be further integrated into therapy and hopefully enhance recovery processes.

Furthermore, the findings in relation to the role of receiving compliments in the onset and maintenance of an ED, and the implications this may have for the use of compliments or praise in treatment, warrants further research. Psychological traits such as self-esteem and perfectionism may influence an individual’s response to praise in treatment, and improving our understanding of these potential influences may have implications for treatment efficacy.

Finally, the findings in this project suggested that the women with BED differed to those with BN and AN in a number of ways, including in relation to control, body image, stigma, access or barriers to services and their views on a shared peer environment. Research into the experiences of BED is an area that is limited in comparison to AN and BN, especially qualitative research, and therefore BED and the ways in which it differs from AN and BN would benefit from being the focus of future research.

6.6 Conclusion

This mixed methods thesis explored perceived causal, maintenance, treatment and recovery factors in EDs, from the perspective of women with lived experience. Their experiences and perceptions were explored quantitively in an online survey and qualitatively with in-depth interviews, providing a valuable insight into a complex group of disorders. Utilising a mixed methods design allowed for the statistical comparison of the perceptions of a wide range of factors, while also capturing a detailed picture of individual experiences and variations dependant on context that would have been unobserved by a quantitative study alone. The high level of convergence between the findings from the quantitative and qualitative studies strengthens the results and subsequent implications. The research also contributes to the very limited qualitative work on the experiences and perceptions of women with BED. The findings provide some thought-provoking new insights into the experiences of these women, whilst supporting and expanding upon existing research, and having implications for clinical practice and preventative initiatives.

The complex nature of EDs was evident, with a multitude of psychological and social factors contributing to the onset and maintenance. Despite some similarities between the diagnostic groups, the variations found reinforce the importance of considering AN, BN and BED as separate illnesses, both in research and during treatment. Furthermore, the individual differences evident in the participants' narratives demonstrate the importance of considering each person's unique circumstances. Many of the psychosocial causal and maintenance factors established also had implications for treatment, whether directly by implementing programmes designed to alleviate underlying factors, or in the way in which treatment is delivered, such as the peer environment. The interconnectedness among the onset, maintenance, treatment and recovery of an ED emphasises that, while separate constructs, there is significant value in considering the journey of an ED holistically. The integrated findings were therefore incorporated into a comprehensive psychosocial model illustrating the factors perceived to be important across the stages of an ED.

In terms of treatment, participants had a range of experiences. Importantly, 19.5% of survey participants had not received specialised treatment, including nearly half of the participants with BED. Furthermore, the majority of interview participants had encountered barriers when attempting access help with their ED. Clearly, there remains a need to make the access to services easier for those with EDs, especially for BN and BED. The main finding in relation to recovery was the overarching concept of a change in perspective, whether this applied to their views of themselves, their ED, or of treatment. Extending beyond individuals with EDs, it is clear that changing societal belief systems that contribute to either the onset or maintenance of EDs needs to be a core preventative measure.

In conclusion, this project provides the first comparison of the perceptions of women with AN, BN and BED, from the onset of their illness and maintenance of their behaviours, to treatment experiences and recovery factors. The findings and implications from this thesis therefore provide a valuable and unique contribution to increasing our knowledge of EDs and stimulating new areas of research to further our understanding, to continue to improve the lives of women with EDs.

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